An ethnographic exploration of the influences around participation in breast screening for women with learning disabilities

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Declaration

No portion of this work referred to in this thesis has been submitted in support of another application for another degree or qualification at this or any other university or institute of learning.

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Acknowledgements

Dedication

The thesis is dedicated to the memory of my four children, who I never held, the dearest friend anyone could be privileged to have, Simon J Harvey, my colleague and mentor Professor Walter J Muir, my adopted niece Kelly Blair and Tormod. All died too young with so much still to give.

To my mother: You were denied your University education due to the Second World War – and you died a few months before I submitted - I hope you are proud of your dyslexic daughter. This is for you.

Abstract

Background

Greater longevity means that many more women with learning disabilities (LD) are becoming eligible to participate in the NHS Breast Cancer Screening Programme (NHSBCSP). The NHSBCSP is used to detect early signs of breast cancer and is open to all women over fifty years of age. Participation by women with LD is lower than that of the general population and little is known about their experience of mammography or what influences their decision whether or not to participate in the programme. This study explored these gaps.

Aim

To explore factors influencing whether or not women with LD participate in breast screening and their experience of having mammography.

Methods

An ethnographic approach was adopted using purposive sampling. One-to-one semi-structured interviews were conducted with 12 women with LD, 10 allied-professionals and 13 carers (10 paid-carers, 3 family-carers). These were supported by periods of focused observation of behaviour related to breast awareness and breast screening. Field-notes were used to support data collection. Data was subjected to thematic analysis, using a blended framework based on McCarthy (1999), Smith (1999) and Smith and Osborn (2003).

Findings

Findings revealed that the women's experience of breast screening was negative, and that this dissuaded them from returning. Factors influencing attendance at breast screening were inextricably linked to the women's level of LD, the level of support they received and the philosophy of care observed in the work place of the paid-carers. These factors were identified as influencing each stage of the breast screening process.

Conclusions

Findings revealed that whilst the women's experiences of breast screening were negative, each woman's journey was unique and depended upon the support provided and their level of LD. For this reason, despite equality of access to breast screening, there was inequality in preparation and delivery of the service.

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Table of Abbreviations

Bild = British Institute of Learning Disability

BSC = Breast Screening Centre

CI= Confidence Interval

CLDN = Community Learning Disability Nurse

COREC = Central Office for Research Ethics Committees

DOH = Department of Health

DRC = Disability Rights Commission

DS = Down's Syndrome

FAIR = Family Advice and Information Resource

GP = General Practitioner

HBM = Health Belief Model

ILF = Independent Living Fund

IQ = Intelligence Quotient

ISD = Information Service Division

IRAS = Integrated Research Application System

LD = Learning Disabilities / Disability

NHS = National Health Service

Chapter 1:   Introduction and Background to the Thesis

This thesis explores what influenced women with learning disability (LD) to attend breast screening. The purpose of this chapter is to contextualise the background to the study and the general area of LD. It is first important to identify the personal drivers for the study. Following this an overview of the definition of LD, a brief history of LD and the changes in policy and philosophy that have affected people with LD are presented. Alongside this, the incidence of breast cancer and explanations about breast screening are documented within the frameworks that surround the screening culture. Finally the overall structure of the thesis is outlined.

1.1.   Personal drivers underpinning this study

Personal and professional reasons have influenced my interest in both LD and the experience of those with LD within the health care system. From a personal perspective, I have a nephew with a learning disability and I have often accompanied my sister and nephew to various hospital appointments. Through this experience, I became aware that few health professionals engaged my nephew (who can speak) in conversation, preferring to talk to my sister or myself about any health procedures (such as x-rays) or examinations that were needed.

My experience in clinical practice as a nurse caring for adults also confirmed these observations. I witnessed nursing and medical staff becoming impatient with people with LD who had poor communication skills. To complicate matters, there was often little information in an appropriate format to help people with LD understand how to keep healthy or understand the medical procedures that they were undergoing. These issues came to the fore when I moved into women's health care and nursed women with LD who experienced menstrual or menopausal problems. I became concerned that these women often had little understanding of the menstrual cycle and did not appreciate the consequences of menstruation (bleeding) stopping, which was often an indication of pregnancy or the menopause.

I chose to explore these observations in greater detail as the basis of my dissertation topic for my Masters Degree which focussed on the menopause in women with LD. My findings highlighted that the women's poor knowledge and a lack of understanding was compounded by a paucity of appropriate information about the menopause (Willis 2008). I was encouraged to extend the masters work whilst working as a research assistant at the University of Edinburgh. Here, I explored the knowledge about the menopause held by women with LD and the paid-carers who supported them during this time. Having subsequently secured funding, I extended the study to incorporate other relevant health-related matters, such as menstruation and cancer screening. The findings from my study identified a lack of knowledge relating to older women's health matters, in both the women with LD and their paid-carers. Attending cancer screening was identified as particularly problematic, with many paid-carers being unsure whether women with LD should go to cervical and breast screening (Willis, Wishart and Muir 2010; Willis, Wishart and Muir 2011).

The findings from these studies led me to consider what influence the women's limited understanding about cancer screening had on their participation in the cancer screening programmes. The Cancer Nursing Fellowship at Edinburgh Napier University presented me with the opportunity to investigate cancer screening in women with LD. Consequently, the fellowship and the focus of this PhD thesis were greatly influenced by my previous research. Furthermore, breast screening was identified as one of the priority health targets set by the Scottish Executive (now Government) in response to inequalities in accessing cancer screening services for women with LD (National Health Service [NHS] Health Scotland 2004). As a result of the above factors, I chose to focus on breast screening in women with LD.

1.2. Prevalence of learning disability and terminology

In this section, I outline the prevalence of people with LD within the United Kingdom (UK) and give the rationale for choosing to use the term 'learning disability' for my study. There are no official statistics indicating precisely how many people there are with LD in the UK (British Institute of Learning Disability [BILD] 2005). BILD (2005) have suggested that prevalence is approximately 1-2% of the population, which in a UK population of 60.2 million gives a total of between 602,000 and 1,204,000 people. More accurate data have been gathered on people with moderate to profound LD because they access health services more frequently due to their additional health needs. It is estimated that they represent 0.35% of the total UK population (210,700 people). In Scotland, the Scottish Government (2007) estimated that there were 122,875 adults with LD known to local authorities. Atherton (2005) has suggested that for every 1,000 people, 20 will have a mild or moderate LD and 3 to 4 a profound or multiple LD. Although prevalence remains uncertain, this represents a significant number of people.

A person is classified as having a LD by the American Association on Mental Retardation (1997) if all of the following identifying characteristics are present:

- Sub-average intellectual functioning (usually an intelligence quotient [IQ] below 75).

- Significant limitations in two or more adaptive skill areas such as communication or academic ability.

- The condition is present from childhood (defined as 18 or less).

The World Health Organisation (WHO) (1997) also has further classifications which are based on the person's IQ which determine the level of disability:

Mild: Approximate IQ ranging from 50 to 69 (in adults having a mental age of 9 to under 12 years).

Moderate: Approximate IQ ranging from 35 to 49 (in adults having a mental age of 6 to under 9 years).

Severe: Approximate IQ ranging from 20 to 34 (in adults having a mental age of 3 to under 6 years).

Profound: IQ under 20 (in adults having a mental age below 3 years)[1].

The classification used by the WHO (1997) has raised a number of concerns, namely that it is highly reliant on IQ and has little regard for the individual: For example, an IQ of 20 correlates to a mental age of 3. However, this does not account for chronological age or the associated life experience, motivations and biological drives, nor does it identify the service needs of the person (Scottish Executive 2000d). Taking account of the criticisms levelled at these definitions, the review document *Same as you* (Scottish Executive 2000d) explored the ways in which the terminology may be used, what it meant across different agencies and professional groups and how it would enable a person with LD to get the services and support they needed. The Scottish Executive (2000d: 103) defined 'learning disability' as: 'a significant, lifelong experience that has three facets:

1. Reduced ability to understand complex information or to learn new skills (in global rather than specific areas)

2. Reduced ability to cope independently.

3. Onset before adulthood (before the age of 18) with a lasting effect on the individual's development'.

There is no umbrella term to describe people with Down's syndrome, Fragile X, William's syndrome and other syndromes (Emerson and Heslop 2010; Gates and Ioannides 2005; Goode 2002). The term 'intellectual disability' is increasingly employed in academic journals, international organisations and some countries (Canada, Australia, Finland) because it is widely understood

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[1] The term profound and multiple LD is also used for severe and profound LD.

and deemed inoffensive across countries and cultures (Fernald 1995; Russell *et al.* 2005; Schalock *et al.* 2002; Taylor and Bogdan 1989; Yuker 1988). Many of the terms used to describe people with LD such as mental handicap and mental retardation have been replaced because of the negative stereotyping which they evoked (Oliver 2001). For example, the term mental retardation was still employed in relation to intellectual disability in North America. In 2011, the House of Representatives passed 'Rosa's Law' which gave a commitment to replace the term 'mental retardation' with 'intellectual disability' in future revisions of health, education and labour policy in Federal and State legislation.

In the UK the term 'learning disability' replaced the term 'mental handicap' because the former is preferred by people with LD and the professionals who work with such people (Emerson and Heslop 2010; Scottish Executive 2000d). Emerson and Heslop (2010) draw attention to the fact that within the USA the term 'learning disability' refers to people with 'specific learning difficulties' such as dyslexia. As there is no overlap at all between the UK and USA usage of the term 'learning disabilities', careful scrutiny of literature from the USA is needed since it may not be relevant to learning disabilities in the context of the UK. The UK also has another peculiarity with its terminology in that 'learning difficulty' is used and seen as interchangeable with learning disability in the context of health and social care for adults. Moreover, within the education sector in the UK, the term 'learning difficulty' includes people who have 'specific learning difficulties' (e.g. dyslexia), but who do not have a significant general impairment in IQ. However, people with specific learning difficulties such as dyslexia, do not have 'learning disabilities'. It is important for scholars working within in the field of LD to remember these peculiarities when undertaking research.

Having considered the problems of definition, a decision had to be made about the term used in my study. The term I employed to describe people with Down's syndrome, fragile X and other similar syndromes in this research was 'learning disability' because the work was undertaken within the UK and the term was preferred by the people themselves (Scottish Executive 2000d). In choosing this term, I acknowledge the problems that arose when studying the North American literature, namely that 'learning disability' referred to people who experience difficulty in learning academic skills or have dyslexia. I also

acknowledge that this is not an internationally accepted term (Gates and Ioannides 2005).

1.3.   An outline of the historical context of learning disability

I include a brief history of learning disability and the main changes in legislation to assist in understanding the marginalisation of people with LD over time. This is important in order to contextualise the area in which the study was conducted. People with LD have been viewed differently by each generation according to the attitudes and beliefs prevalent in society at the time. The Romans left children with LD to perish, believing that they had angered the gods, whereas by the fifteenth century many were considered to be witches and were burnt (Harris 2006). Prior to 'industrialisation', some people with LD took a full and active part in society, but their social demise came with the move from agricultural-based livelihoods to those that increasingly depended on intellectual ability (Atherton 2007). In essence, the move from agricultural to industrialised occupations precluded people with LD from being regarded as useful members of society (Digby 1996).

Their inability to undertake industrial work meant that people with LD were more likely to live in poverty, commit crime and for women with LD to become prostitutes (Harris 2006). The Poor Law Amendment Act 1834 offered some respite by segregating those considered unable to contribute to the economy and placing them in workhouses, where they worked in return for food and shelter (Atherton 2007). The Idiots Act 1886 was the first piece of legislation that acknowledged people with LD, enabling them to be admitted to 'specialised asylums', although the subsequent Lunacy Act 1890 did not discriminate between those with mental illness and those with LD (Atherton 2007).

The plight of people with LD was compounded further due to the eugenics movement which postulated that LD was heritable (Digby 1996). This assertion focused attention on reducing the capacity of people with LD to reproduce in order to select out heritable traits that were considered undesirable (Radford 1991). It was not until 1904 that a Royal Commission was set up to investigate the 'problem of the feeble minded' (Digby 1996). This was followed by the

Mental Deficiency Act 1913 which identified people with LD as being distinct from the mentally ill and enabled them to be detained (but which was never enforced due to the outbreak of the First World War). Placing people with LD in institutions or hospitals occurred primarily during the interwar period following the findings of the Wood Report (1929), when institutional living became the norm for most people with LD (Atherton 2007). Despite this, there remained an unknown number of people with LD who lived at home with their family.

Concerns regarding the suitability of institutional care for people with LD began to be moved up the political agenda after the formation of the European Convention on Human Rights (1950) and following the findings of The Howe Report (1969) which highlighted the poor conditions in which people with LD were living in these institutions (Atherton 2007). It was at this point that the move began towards de-institutional living, as advocated by work from the Department of Social Services (1971) and *The Jay Report* (1979). *The Jay Report* also gave rise to the adoption of the principles of normalisation within service provision for people with LD (Wolfensberger 1972). Normalisation aimed to enable people with LD to live as close to the 'normal' conditions enjoyed by those without LD. Latterly, it was associated with the closure of hospitals and institutions in favour of using services in the community (Atherton 2007; Oakes 2007).

Subsequent policy and legislation culminated in the NHS and Community Care Act 1990. This saw people with LD move from institutional care to living in their own homes within the community. It is thought (although there are no definitive statistics) that the majority of people with LD still reside in their own homes today, testimony to the policy of including them within mainstream society rather than segregating them from it.

1.4.   Health policy and people with LD

This section presents a brief summary of Scottish health policy before proceeding to outline the health priorities relating to the LD population. This is deemed important since the health needs of the general population differ from those of people with LD. Devolution under *The Scotland Act* (1998) presented

an opportunity for health strategy and policy in Scotland to be more responsive to Scottish needs and to improve the health of the Scottish people. Scotland has always had a poor health record and these concerns were seen to be addressed in legislation such as the white paper *Towards a Healthier Scotland* (Scottish Executive 1999) and *Our National Health: Delivering for Change* (Scottish Executive 2001). This legislation pledged to tackle health inequalities and reduce and prevent the three major killers within the Scottish population: cancer, stroke and coronary heart disease (the 'big three'). A number of strategies were initiated aimed at tackling the 'big three' by reducing incidence and improving services. Whilst investment continued to bridge the health inequalities gap, the responsibility for health was deemed to reside with the individual (Scottish Executive 2005). Additionally, documents such as *Better Cancer Care* (Scottish Government 2008) were also responding to an increasingly ageing population. This identified a need for more community-based services rather than acute services in order to help people live with and manage long-term conditions such as cancer. Current policy, such as *The Healthcare Quality Strategy for NHS Scotland* (Scottish Government 2010), is now concentrating on putting people at the heart of everything the health service does.

People with LD have health priorities which differ from the general population. Priority areas for this group include sensory (eye and ear) and dental needs. The commonest cause of death has been found to be from respiratory disorders, rather than stroke or heart disease (Disability Rights Commission [DRC] 2006; Raitasuo *et al.* 1997; Turner and Moss 1996). Furthermore, many people with LD have competing health concerns alongside their 'learning disability' and although they require access to specialist services, they often do not access these services (DRC 2006; Melville *et al.* 2006; Scottish Executive 2004c). Even when services are accessed, the care received has not always been appropriate, as was documented in reports such as *Death by Indifference* (MENCAP 2004).

With greater life expectancy due to advances in medicine (people with LD rarely lived beyond 30 years of age until recently, while many can now live well into their 80's), people with LD are now exposed to the same illnesses and diseases

of old age such as cancer seen within the general population (Bittles, Patterson and Sullivan 2002; Tuffrey-Wijne *et al.* 2007b). This makes access to early detection programmes such as breast screening, good health and cancer care an important consideration for people with LD. Despite this, people with LD have been found to experience more health inequalities in cancer screening and end-of-life care (Davies and Duff 2001; Hogg and Tuffrey-Wijne 2008; Tuffrey-Wijne 2003; Tuffrey-Wijne *et al.* 2009). Furthermore, despite people with LD being one of the most socially and economically disadvantaged groups in Scotland, mainstream health policy has rarely addressed the health inequalities within this population (Scottish Executive 2000d). However, the publication of *Better Cancer Care* (Scottish Government 2008) highlighted the low uptake of cervical screening in women with LD, and demonstrated a marked change in tackling these inequalities.

This change in focus in health policy is welcome because health issues such as cancer in this population should not be ignored. Cancer-related illnesses account for 16% of all deaths in people with LD (Baxter and Bradley 2008). Within the population, diagnosing cancer has been found to be problematic, with many cancers being presented at a more advanced stage because of the delay in diagnosis or the cancer being missed altogether due to the inherent communication problems when dealing with this group (Kastner, Nathonson and Friedman 1993; Tuffrey-Wijne 2007a). Furthermore, many people with LD have numerous and more complex health problems which are often poorly managed and can, if left untreated, lead to cancer (Baxter and Bradley 2008; Hogg, Northfield and Turnbull 2001; Van Schrojenstein *et al.* 2001). For example, *Helicobacter pylori* and gastro-oesophageal reflux are commonly found in people with LD and have been linked to pre-malignant conditions such as Barret's oesophagus (Sullivan *et al.* 2007). This highlights a need for more appropriate support and service provision if the health requirements of this population are to be met.

The publication of *Same As You? A Review of Services for People with Learning Disabilities* (Scottish Executive 2000d) was the first major survey of services for people with LD in Scotland for over twenty years and was one of the first policy initiatives under devolution. The document set out the service

and support needs for the future through 29 wide ranging recommendations. These included initiatives such as setting up a centre offering training, information and support to professionals, carers and people with LD, assisting professionals to identify early signs of dementia and for Local Authorities to provide better access to public transport. This was followed by *Promoting Health, Supporting Inclusion: The National Review of the Contribution of all Nurses and Midwives to the Care and Support of People with Learning Disabilities* (Scottish Executive 2002) which examined nursing services across Scotland and identified current and future nursing needs and education. The findings demonstrated inequalities in the health of people with LD and a need for support with health needs across the life span. From this came the *Health Needs Assessment Report: People with Learning Disabilities in Scotland* (NHS Health Scotland 2004) which aimed to develop and plan future of services for children and adults with LD. A key element highlighted within all these documents was the need for joint working initiatives across the social work, education and NHS sectors. Although joint working is advocated it is important to understand the changes to the living circumstances and service provision for people with LD. These changes are identified in the next section.

1.5.   Changes within the learning disability environment

Having set out the historical and health policy contexts, a summary of the changes within the service provision for people with LD will be presented. Over the last two decades the lives of people with LD and the services offered to them have changed significantly (Barr 1995; Emerson 2004; Oakes 2007). The biggest change that occurred came under the NHS and Community Care Act 1990 which saw a 'rights-based' policy come into fruition. This resulted in many people with LD moving out of institutions and hospital care and into the community. It also changed the structure of service provision as it split the role of health authorities and local authorities by changing their internal structure, so that local authority departments assessed the needs of people with LD and then purchased the necessary services from 'health providers' such as the health authority. This move changed how people with LD lived their lives and accessed health services. For this reason, social services were expanded to meet the needs of people with LD in the community.

Those living within an institution or hospital rarely went into the outside community unless for an outing, family visit or occasionally a holiday. All social, emotional and health needs were met by the staff (mainly nurses and doctors) within the institution or hospital. Most people with LD in the UK today live in their own home rather than an institution. This has seen a shift in care from a medical model of care to person-centred planning. Person-centred planning is seen as a process of learning about a person, their history, experiences, what is important to them and what they want from life (Sanderson 2007). Most people with LD will have a care package which includes home and day-care services. Day-care varies from attending college, work or a day centre (a designated centre specifically for people with LD which provides different activities such as art, music, cooking and drama), which may be run by voluntary groups or social or health care organisations. Recently, the introduction of the Independent Living Fund (ILF) has replaced the Direct Payment System in Scotland (whereby local authorities gave money directly to people with LD who were able to manage the money effectively). The ILF displays a number of strengths, such as allowing people with LD the choice to have one-to-one care (care given by one dedicated person) rather than going to a day centre, but also some limitations, since such care has also been seen to isolate them (Mencap 2010).

Home care refers to the care the person receives within their own home. There are no definitive statistics for the number of people living within the community, although an estimated 7,497 adults with LD in Scotland were living in their own tenancies or were owner-occupiers (Scottish Government 2007), or for those who live within family homes. However, it has been estimated that hospitals, care homes and day care serve about 17,000 people with LD in Scotland. Hospitals are seen to care for 2,450 people with LD, whilst social care deals with 14,300 (Scottish Executive 2000d). The range of living circumstances differs. Some people with profound or severe LD are still looked after in a hospital environment because they are unable to be supported in their own home or in local community settings. These people will receive 24-hour care, from paid-carers from the social or voluntary sector and/or trained nurses.

A minority of people with LD remain within the family home and are looked after by their family (again there are no definitive statistics). Family carers are

entitled to receive an attendance allowance and access to respite-care
(a provision for a short break to enable carers to pursue their own needs).
Respite-care has been found to be beneficial to the health and wellbeing of
family-carers (Scottish Executive 2000d). This leaves a small number of people
with LD who live independently with minimal assistance from the voluntary
sector, social services, friends or family.

The majority of people with LD live in accommodation with some sort of support
from voluntary, social or health care organisations. No available statistics were
found to reflect the type of accommodation in which people with LD live. Most,
however, will live in a house or flat either by themselves or which they share
with a number of other people (ranging from 1 to 20, plus others such as
carers). They may have the support of a paid-carer, ranging from a few hours
for help with paying bills and cleaning through to working in the house for up to
24 hours. Some people with LD may have a dedicated paid-carer with them all
the time, providing what is known as one-to-one care. However, it is fair to say
that no two people with LD will have exactly the same support or living
environment and will be supported by a range of individuals and organisations.
This can on occasions lead to problems in terms of defining who has overall
responsibility for their care.

This move into the community has changed how people with LD access health
services. Previously the health of people with LD was the responsibility of the
hospital or institution staff. Today, for those within the community access to
health services is determined by general practitioners (GP). This is problematic
because GPs have little experience of working with people with LD and readily
acknowledge their limited training or knowledge about the health needs of this
group (Ng and Li 2003; Philips *et al.* 2004). It also limits the contact people with
LD have with specialists in LD since GPs and health professionals in the acute
medical sector will have received limited training about the health needs of this
group (Hammes and Carlson 2006). To counter this problem, Community
Learning Disability Teams (CLDTs) have been established. These teams
comprise a number of specialists such as consultants in psychiatry, community
LD nurses, speech and language therapists, occupational therapists, all of
whom have received specific training in working with people with LD. To be

seen by the CLDT, a referral is needed by the GP, other health specialist or the person themselves. Depending on demand and resources, this can mean being placed on a waiting list. The move into the community was seen as the way forward but it has presented, and continues to present, a number of problems in meeting the health needs of this group.

Along with the changes described above, there have also been changes within the role of the LD nurses following a review undertaken by the Scottish Executive (2002). This review identified that all nurses and midwives (not just those who had been trained in LD) needed to have some understanding about how to work with people with LD and their carers. For nurses who trained as LD nurses their remit changed from the long-stay, hospital-based environment (where people with LD would live permanently in the hospital) to a community environment, where they worked as a Community LD Nurse (CLDN) as part of the CLDT. This meant their 'caseload of clients' would be constantly changing as clients would be referred by a GP, another professional or the person themself. The biggest change was that the role of the LD nurse was largely replaced by paid-carers.

Paid-carers are individuals who are usually employed within the social care sector. The hours worked vary depending on individual circumstances (ranging from a few hours up to the maximum of 48 hours per week) and the employing organisation. Average payment can range from the minimum wage (£5.80 per hour) and upwards. Training is also variable, although most organisations must adhere to the National Care Standards under the The Regulation of Care (Scotland) Act 2001. Regulation until April 2011 was overseen by the Care Commission but this has now passed to a new body, Social Care and Social Work Improvement Scotland, whilst regulation of independent healthcare has passed to Healthcare Improvement Scotland. These standards uphold values such as dignity, choice and respect. Not all paid-carers have training in health matters and this again depends on the organisation or agency and client group the paid-carer is supporting. Concerns have been raised about the standard of training, as many paid-carers are not necessarily experienced in caring for people with LD and may inadvertently discount health problems or not

recognise symptoms of illness or disease (Janicki *et al.* 2002; McCarthy 2002; Patja *et al.* 2001; Sullivan *et al.* 2003).

Another significant change for people with LD was made at the turn of this century, namely the Adults with Incapacity (Scotland) Act (Scottish Executive 2000a). This Act provides a framework for managing the welfare and finances of adults (defined as 16 years and over) who lack capacity due to mental health problems or communication difficulties and this includes people with LD (Scottish Executive, 2000a). Capacity has been defined as the ability to understand information relevant to a decision or action and to retain the memory of making that decision (Scottish Executive 2000c). Doctors have the principal responsibility for the formal assessment of capacity, although a multi-disciplinary assessment approach is advocated (Scottish Executive 2000c). For those who do not have capacity, a welfare guardian can be appointed through the justice system. Once guardianship, whereby another person takes responsibility for the person with LD, has been obtained, decisions, including medical decisions, must then be channelled through that individual. However, there are certain exceptions in place for medical decisions where the adult has no welfare guardian. In these circumstances a doctor is authorised to provide medical treatment subject to a number of conditions such as it being in the person's best interest or involving a life-threatening condition. If there is disagreement, a second medical opinion must be sought. Despite this, care givers and care providers are often unaware that people with LD can make their own decisions (Carlson *et al.* 2004; Dunn *et al.* 2006; Haw and Stubbs 2005). This suggests that although the Act has given more power to people with LD to make decisions, this has not been fully implemented in practice. Alongside this there have been other changes which have had an impact on the way that people with LD are viewed and these are explained in sections 1.6 and 1.7 below.

1.6.   Normalisation

The concept of 'normalisation' was introduced in Scandinavia in the 1950s. It suggests that people with LD should have access to support so that they can experience patterns and conditions of everyday life that are as similar as

possible to those of mainstream society (Beirne-Smith *et al.* 2006; Nirje 1992; Wolfensberger 1972). In Britain, the principle of normalisation was embraced through O'Brien and Tyne's (1981) five service accomplishments. These advocated that people with LD should use the same services as everyone else (*Community Presence)* and maintain their relationships with family and friends (*Community participation*). They also stated that people with LD should be supported to live more independently (*Competence*) and have the same *choice* and *respect* afforded to them in decisions about services and their lives as was enjoyed by anyone else.

The ideas of normalisation were implemented in policy through legislation such as the NHS Care in the Community Act (1990) and led to changes in areas such as where people with LD live – the community rather than in an institution. Critics of normalisation suggested that while people with LD may have equal rights they were not participating in or integrated into society in a meaningful way (Emerson 1992). Gilbert (1993) argued that normalisation was driven by philosophy and did not constitute a client-centred framework insofar as it treated people with LD as a homogeneous group and failed to recognise their unique qualities. Recognising these limitations, Wolfensberger (1983, 1998) advocated replacing the term normalisation with 'social role valorisation' and moving policy away from a focus on providing 'normal services' to a greater emphasis on the development of valued social roles for people with LD (Atherton 2007; Barr 1995; Deeley 2002). The main crux of the argument was that people with LD were perceived by 'society' as being 'different' and of less value than everyone else; hence social role valorisation set out to emphasise the valued roles that people with LD could play within society and highlight the impact which devaluation of these roles could have on individuals. More recently, Wolfensberger (1999) has adjusted his definition of social role valorisation to 'the application of what science can tell us about the enablement, establishment, enhancement, maintenance, and/or defense of valued social roles for people' (Flynn and Lemay 1999: 125). Since then there have been other shifts in understanding.

1.7.   Social inclusion

Social role valorisation and normalisation have now been replaced with the concept of social inclusion. MacIntyre (2008) has suggested that there is no single definition of social inclusion, hence strategies promoting social inclusion are varied. One definition of social inclusion suggests that it is about reducing inequalities between the least advantaged groups and communities and the rest of society by closing the opportunities gap and ensuring that support reaches those who need it most (Scottish Government 2012).

In 2004 the Scottish Executive introduced targets for reducing inequalities which focused on barriers in relation to health, employment and communities. In her review MacIntyre (2008) noted that the Scottish Executive believed health improvements could be achieved by regenerating disadvantaged neighbourhoods in order to improve quality of life, health status and access to high quality services. However, the main focus was in terms of increasing employment to increase mental health and well-being (Huxley 2001). Accepting that employment can provide a route out of poverty to attain better goods and services, employment remains problematic for people with LD. This is because there are many barriers to work such as physical access problems as well as employment practices that prevent people with LD being able to gain employment (MacIntyre 2008; Walmsley 1991).

Core principles of social inclusion underpin the policy, legislation and service provision for people with LD in Britain today (Wullink *et al.* 2009) in documents such as *Valuing People* (Department of Health 2001a), *Same As You* (Scottish Executive 2000d), and *Health Needs Assessment Report: People with Learning Disabilities in Scotland* (NHS Health Scotland 2004). However, the framework and policy which have developed as a consequence of this have been strongly criticised. There have been mixed reviews concerning the impact on services for people LD of both *Valuing People* and *Same As You* (Fyson and Simons 2003; Robertson *et al.* 2005). An area that has been singled out in healthcare is that of cancer screening, with suggestions that women with LD are not accessing or being put forward for screening and are also not being regarded as equal women in society.

Criticisms can be made of both normalisation and social inclusion in terms of women with LD being accepted as equal to other women (Brown 1994; Chappell 1992; Deeley 2002; McCarthy 1999). Strong arguments have been put forward for equal sexual rights. Institutional living was seen as limiting the opportunities for sexual relationships to develop amongst people with LD because service providers viewed women with LD as vulnerable to and at risk of sexual abuse rather than equal women with a right to a sex life (Garbutt 2008). This has been seen to devalue their 'womanhood' since asserting a right to a sex life serves only to heighten their visibility as 'vulnerable' rather than increase their integration and acceptance into society as a sexual equal (Brown 1994; McCarthy 1998; Williams and Nind 1999; Walmsely, 2000). While more liberal attitudes towards sexual relationships between people with LD are being found (Holmes 1998), traditional taboos still remain (Duduay 2011; Oakes 2007). Women with LD still experience high levels of sexual abuse and sexual intercourse which is neither gratifying nor fully consensual (McCarthy 1999). This is often due to sexual matters not being discussed or the reproductive cycle acknowledged (Duduay 2011; McCarthy 1999; 2001; Rodgers 2001; Willis, Wishart and Muir 2011).

The point that Brown (1994) and McCarthy (1998) make about 'womanhood' being devalued is that, despite social inclusion, women with LD are still seen as different and not equal to other women. They are not seen as equal in terms of having sexual relationships, but nor are they accepted as equal to women in the general population. Evidence for this can be found in the literature on breast screening which has suggested that when GPs scrutinised lists of women eligible for breast screening (this practice has now been terminated), women with LD were often removed from the lists or were considered as not needing the procedure (Davies and Duff 2001; McIlfatrick, Taggart and Truesdale-Kennedy 2011). If women with LD are to be accepted as equal to women in the general population, their access to and take-up of breast screening has to be improved and their views on this subject explored.

1.8. Inclusive research

Changes in the way that people with LD were viewed under normalisation were reflected in the way that research on people with LD was conducted. Instead of being tested (using IQ tests) and analysed by researchers, under the parameters of 'inclusive research' the study of people with LD has moved towards acknowledging their experiences (such as going for breast screening) or improving their status in society (Northway, Parker and Roberts 2001; Rioux and Bach 1994). Such research generated outcomes more geared towards improving their quality of life and service needs (Oliver 1992). Inclusive research maintains that research conducted on people with LD should be undertaken in closer consultation with them and even include them in the research process (Chappell 2000; Kiernan 1999; Northway 2000; Walmsley 2004a).

This has led to a predominance of qualitative studies because they enable the views and experiences of people with LD to be heard more clearly. This is in line with prevailing trends in health service research which has moved towards an emphasis on patient involvement and experience, especially for more marginalised service users such as people with LD (Scottish Executive 2005). The concern for people with LD has been that, despite being the best informants about their experiences, they are less able to express their opinions due to their limited verbal ability. Hence there is a need for inclusive research (Chappell 2000; Stalker 1998). Unfortunately, inclusive research has also been seen to reinforce the exclusion of people with LD insofar as other marginalised groups do not require a distinctive research approach (Walmsely and Johnson 2003).

Inclusive research is an umbrella term that covers two disability research traditions: emancipatory and participatory research (Gilbert 2004; Walmsley 2001). Emancipatory research has been seen to place the researcher's expertise at the disposal of people with disabilities, enabling them to plan, carry out and write-up the research (Oliver 1992; Kiernan 1999; Walsmsely 2001). This approach has raised a number of issues, including that people with LD often perceive themselves as less powerful than their non-disabled

counterparts, and whether they fully understand the research process given the heavy reliance on intellectual skills which it involves (Kiernan 1999). These have been addressed through the use of a 'team approach' with people with and without LD working together (Riddle *et al.*1998; Walmsley 2001; Walmsley 2004b).

In contrast, participatory research has placed emphasis on the opportunity for people with LD to participate in the research whilst leaving the researcher to retain control of the work being undertaken (Chappell 2000; Walmsley 2001). This has meant that the views and voices of people with LD are heard and conveyed through the findings of the research (Booth 1996; Burke *et al.* 2003; Knox, Mok and Paramenter 2000; Walmsley and Johnson 2003). This has prompted researchers to develop tools such as talking mats (a communication framework involving sets of symbols) or the writing hand technique, where a supporter listens to and records the words of the person with LD to extract the narratives that they contain (Brewster 2004; Walmsley and Johnson 2003). This has also prompted evaluation of whether research tools such as focus groups are appropriate means of data collection (Gates and Wright 2007). Although participatory research has been criticised as being a form of advocacy and not addressing the power imbalance between the researcher and those being researched, it remains the choice of those working in the field. This is because it has enabled the views of the more disabled in society to be heard. This approach also acknowledges that involvement and participation in all aspects of the research process are not always possible (Walmsley and Johnson 2003).

Thus far I have outlined normalisation and suggested that it has not yet achieved the goal of women with LD being regarded as equal to women in the general population. However, inclusive research has become a powerful force for those undertaking research in the field of LD to be mindful of working for improvements in services and the experiences of people with LD. The remainder of this chapter focuses on breast screening, first by providing the reader with some understanding of breast cancer and breast screening in women with LD, then by outlining some of the psychological models related to screening.

1.9. Breast cancer in women with LD

Having analysed the learning disability field in general terms, attention is now turned in the following two sections to the specific focus of my study, namely screening for breast cancer. In this section, the incidence of breast cancer in the UK is outlined and then related to risk and incidence in women with LD. The next section examines breast screening and sets the context for its application to women with LD.

Research has shown that breast cancer (essentially a cancer of the breast tissue) is the most prevalent form of cancer in women, with around 16,449 new breast cancers being detected and 12,000 women dying from the disease each year in the UK (Cancer Research UK 2010). In Scotland 4,200 cases of breast cancer (15%) were reported in 2008 (Information Services Division 2010). However, the incidence of breast cancer in Scotland in women with LD is not known. Treatment options for breast cancer can involve a combination of interventions including surgery, chemotherapy, radiotherapy or hormonal therapy. Earlier detection of breast cancer through the National Health Service Breast Cancer Screening Programme (NHSBCSP) has also reduced the need for more aggressive treatment options (NHS Health Scotland 2003). The high incidence of breast cancer and less aggressive treatment have both helped to justify having a screening programme.

Around 5–10% of breast cancers are inherited and the genes BRCA1 and BRCA2 have been identified as being responsible (Macmahon 2006; McPherson, Steel, and Dixon 2000; McPhearson *et al.* 2006). Women with an inherited component have an enhanced risk of breast cancer and should be offered preventative treatments such as genetic counselling and/or breast screening from an early age. After hereditary factors, female sex and increasing age amplify the risk of getting breast cancer, although a number of risk factors are associated with the development of the disease. These include excessive alcohol intake (Tjonneland *et al.* 2007), high fat diets (Blackburn *et al.* 2003), low physical exercise and obesity (Key *et al.* 2003), being nulliparous (not having children) and early menarche (periods commencing) or late menopause (Machia 2001; Macmahon 2006; McPhearson *et al.* 2006).

The incidence of breast cancer in women with LD has been found to be lower than that of women in the general population (Jancar 1990; Jancar and Jancar 1977). However, there are two exceptions where reports of a similar incidence to the general population exist (Patja *et al.* 2001; Van Schrojeinstein Lantman-de Valk *et al.* 2002). Apart from Schneider, Kieffer and Patenaude (2000), little has been written on family history and breast cancer in women with LD. A fuller account of incidence is given in Chapter two. In terms of risks factors associated with breast cancer, this group has higher incidence of obesity (higher in women than in men), lower levels of exercise, and a poorer diet compared to the general population (Bell and Bhate 1992; Rimmer, Braddock and Fujiura 1993; Rimmer 1994; Melville *et al.* 2005; 2006) but are low consumers of alcohol (Noonan Walsh and Heller 2002). Although no exact figures are available for the number of women with LD having children, nulliparity is more often reported (Carlson and Wilson 1996; Tarleton *et al.* 2007).

Women with LD have been found to have some protective factors against breast cancer. Oestrogen (female hormone) for example, has been found to make breast tissue more susceptible to breast cancer (Miller and Sharpe 1990) and women with LD have lower oestrogen levels than the general population as well as an earlier menopause (Carlson and Wilson 1996; Carr and Hollins 1995; Cosgrove *et al.* 1999; Schupf *et al.* 1997, 2003; Seltzer, Schupf and Wu 2001). History of earlier menarche in women with LD was often not available due to poor documentation, lack of family history or poor memory of the event (McCarron and Pekala Service 2002).

1.10. Breast screening in women with LD

Within the UK there are a number of screening programmes, such as health screening (blood pressure, cholesterol), genetic screening (pre-natal and hereditary conditions) and the national cancer screening programmes relating to bowel, breast and cervical cancer. The NHSBCSP commenced in 1988, and was based on the findings from the Forrest Report (1986) which recommended the introduction of breast screening after reviewing trials of breast screening within the UK and internationally. Publication of *The Health of the Nation:*

Strategy for Health in England (1992) suggested screening women for breast cancer could reduce mortality by up to 25% amongst those screened. To make it viable, a 70% acceptance rate was needed. The NHSBCSP is now nationally co-ordinated, has national clinical standards and is free to all women registered with a GP aged 50–64 in Northern Ireland, 50–70 years in Wales and Scotland, and 47–73 years in England. In the UK, approximately 133,189 women were screened and 17,013 cancers were detected in the period from April 2009 until March 2010 (NHSBCSP 2011).

Breast screening is organised by area and is related to the woman's postcode. Invitations to attend for breast screening are offered on a three-yearly basis in each postcode area. Invitations are produced automatically by the breast screening centre (BSC) from the list of women who have registered with GPs in that postcode area and are sent directly to the woman herself. Previously, the BSC would send a list of women eligible to be screened to their own GP, who would scrutinise the list and eliminate those women they felt were not eligible, such as women who had both breasts removed, were too frail to attend and those whom the GP believed would not tolerate the procedure (Weller 2006). Women outside the age of eligibility who want to be screened can either contact the BSC individually or ask to be referred by their GP. If the woman decides not to participate in breast screening, surveillance measures such as breast awareness (where the woman feels and visually observes the breast to check for abnormalities) can be undertaken (Cancer Research UK 2010).

Unlike cervical screening, where GPs have a monetary incentive for ensuring 80% of women on their registers are screened, no such incentive exists for breast screening. There are two choices of where to be screened: either the designated BSC or mobile units (which are similar to a portacabin) placed in convenient locations such as shopping centres. If accepted, a mammogram (x-ray of the breast) will be taken and results reported within 7–14 days. Around 5% of women are recalled after their first mammogram for further tests, due to inadequate or suspicious mammograms (Cancer Research UK 2010).

Women with LD are equally eligible to attend for breast screening. However, there have been a number of measures put in place to make the process of

breast screening more accessible to them. Information for women with LD is available in an accessible format in the publication *An Easy Guide to Breast Screening* (NHSBCSP 2006). Furthermore, guidelines such as *Equal Access to Breast and Cervical Screening for Disabled Women* (NHS Cancer Screening Programme 2006b) have enabled practitioners to have clear guidance on how to perform and assist disabled women (including women with LD) during breast or cervical screening. In addition, BSC can offer a number of other services such as appropriately tailored letters in an accessible format to invite the woman to screening. They could also give them more time to undergo the procedure by offering a double appointment and enable them to look round the centre prior to attending for their screening appointment. However, these cannot be implemented unless the BSC staff are informed by the women or their paid-carers of the need for such measures. There are no statics to show how many women with LD take up this option or how many or how often BSCs provide this service.

From its inception, doubts over the benefits of breast screening have been raised. It is estimated that for every 2000 women invited for screening over a 10-year period, only one would have her life prolonged, whilst 10 otherwise healthy women would be diagnosed as having breast cancer, only because they attended for screening (Gøtzsche and Nielse 2009). This is because breast screening detects slow-growing tumours which would not cause any adverse effects if left untreated (WHO 2002). Hence, there is a suggestion that more emphasis should be placed on ensuring women are fully informed about the benefits and harms of participating in the programme, especially in respect to the safety of mammograms (Gøtzsche and Nielse 2009). This is pertinent for women with Down's syndrome, as they have an inability to remove radiation from breast tissue (Satgé and Sasco 2002). However, for women with LD generally, weighing up the risks and benefits of attending is problematic because of the difficulties they have in this area of problem solving (Keywood, Fovargue and Flynn 1999).

1.11. Screening as a form of social inclusion

Screening programmes go against social norms, because they require people to attend for a health intervention when no recognisable symptoms are present. Despite this, going for cervical or breast screening is seen as the 'norm' for most women (Armstrong 1995; Harlan *et al.* 1991). Within society attendance at screening can be interpreted as a 'social norm' because attendance is expected and therefore maintains that 'norm'. It could be argued that the low uptake of screening by women with LD demonstrates that these women have not been 'normalised' into this behaviour (i.e. screening is not seen as part of their normal womanly routine) and therefore have not achieved inclusion. However, it is more likely that these women have not been able to assert their rights to being seen as equal to women who do not have LD. For this reason, ascertaining factors that facilitate and inhibit attendance at screening could help providers increase uptake and encourage women with LD to undergo the procedure. Investigation of what increases uptake has been explored through the use of health beliefs (Marks *et al.* 2005; Ogden 2007), but before discussing these models it is important to situate the rise of screening.

Screening can be regarded as a form of social control because those women who choose not to attend can become stigmatised by health professionals (Cribb 2002; Skrabanek 1990). Screening is part of the public health agenda. Social theorists have argued that the arena in which public health operates is influenced by the idea of bio-power (Foucault 1991). The concept of bio-power emerged as a response to the economic and political problem of 'population' in the eighteenth century. During this period the population became the workforce or 'machinery of production'. Economic growth and wealth became linked to the population insofar as it represented the means of production. The suggestion that the country's wealth was reliant on the population became of interest to the state. This was because births, incidence of disease and deaths could have an important impact on production. In consequence, there was a concern to ensure that the population was healthy. Arising from this concern was a new form of power that Foucault (1991) termed as 'governmentality'. This was seen to move the power to the government which in turn gave rise to the emergence of social control.

A way of enforcing social control was through surveillance and analysis of populations. Populations could be categorised in terms of their specific phenomena and this division could help to establish what was normal and what was considered to be deviant. These factors could be used to establish norms which would further divide the population into those within it who contributed to society and those who did not (Rose 1996). This has parallels with the history of people with LD and within social inclusion of women with LD (Brown 1994, McCarthy, 1999). Dividing the population in terms of contributors and non-contributors meant that individuals within the population could be controlled through the set of standards and values associated with so-called 'norms' (Dean 1996). These concepts of surveillance, norms and social inclusion can be applied to health promotion. This is because within health promotion there occurs the 'production of norms', such as cancer screening programmes, which use similar principles to normalise the population (Cribb 2002; Petersen and Lupton 1996).

At the core of health prevention are the ideas that risks to health can be 'managed' and managing these risks is the norm. It is normal for the population to ensure that these identifiable risks are monitored. Therefore individuals are encouraged in the preventative health arena of public health to manage their own 'risk profile' (Ogden 2007). However, not everyone accepts the message of 'risk management' and conforms to these norms (Lupton 1997). Those that do not manage their risk are seen as deviant (Cribb 2002). Much of the surveillance of the population's health has tended to focus on the female body, for example cervical and breast screening. This in turn has been interpreted as the regulation of female sexuality through a system of patriarchy (Cribb 2002). Feminist theorists such as Bordo (1997) suggest that surveillance creates 'normality' within the female psyche. Thus the concept of bio-power can be seen to give rise to the notion surveillance which has then been used to control and govern the female body (Sawicki 1999).

Within the screening debate, the idea of *surveillance medicine,* the observation and monitoring of apparently healthy populations, has been propounded (Armstrong 1995). Armstrong argues that medicine has acted along with the government as a means of controlling and regulating populations. Thus the use

of screening programmes authorises medical staff to examine individuals through legitimising surveillance within the public health agenda. Public health is a justifiable conduit used as a means of alerting the population to risks within society; and the way to monitor these risks advised by those within public health is through observation and surveillance (Armstrong 1993). The practice of traditional medicine, which was once the preserve of the hospital, has been extended to the wider society and now encourages individuals to monitor their own health. This has also been seen to deconstruct health beliefs within traditional medicine which held that those who seek medical help are those who are ill. But now under medical surveillance the entire population is on a continuum and no-one is ever truly healthy (Armstrong 1995). Surveillance of the population's health, and indeed that of individual health, has extended to everyone, healthy and unhealthy.

The intrusion of health surveillance has been termed 'the management of normality' (de Swaan 1990). All individuals now live under a medical regime, whether it is because they are ill (albeit these individuals endure heavier scrutiny from the medical fraternity) or in the everyday life of an individual through warnings about alcohol, diet and smoking. It is within this context that breast screening as an early detection programme can be considered. Breast screening is a form of surveillance administered under the medical gaze which is used to detect breast cancer. Breast cancer is a disease that is often asymptomatic and invisible. Attending breast screening can be seen part of a woman's normal routine, hence women are 'normalised' into having their breasts examined every three years irrespective of whether they have detected any symptoms. As this procedure is open to all women, all women must be included. This is the reason for the suggestion at the start of this section that women with LD have not been normalised into going for breast screening and hence are not equal to women in the general population and that there is duality in terms of inclusion. For those women who deviate from the norms, such as not attending for breast screening, it is necessary to explore the reasons for their non-attendance. One area of psychology that provides some explanation for this is the predictive models used within the field of health beliefs.

1.12. Health beliefs

Health beliefs have often been linked to screening up-take and have been measured using predictive models (Ogden 2007). These models are derived from psychology and generally take two forms, the cognitive and the social.

The Health Belief Model (HBM) is a cognitive model (a model looking at the thought processes) and has attempted to explain and predict health behaviours by focussing on the attitudes and beliefs of individuals. Developed in 1966 by Rosenstock, the model has been adapted to explore a variety of long and short-term health behaviours. The HBM is based on the understanding that a person will take a health-related action (e.g. attend mammography) if that person:

1. Feels that a negative health condition (cancer) can be avoided,

2. Has a positive expectation that by taking a recommended action, she will avoid a negative health condition (going for breast screening will detect malignancy or confirm the absence of cancer); and:

3. Believes that she can successfully take a recommended health action (utilise screening).

Criticisms of the model have suggested that while the model describes the women attending breast screening, it did not consistently predict behaviours (Yarbrough and Braden 2001). Ogden (2003) noted that rather than describing behaviour the models created and changed both cognitions and behaviour. Furthermore, the application of this model to women with LD is not known as no literature could be found using this model with this group.

The Theory of Reasoned Action (TRA) model has been used to predict behaviour and has been central to the social psychological debates concerning the relationship between attitudes and behaviour (Ajzen and Fishbein 1975; Fishbein 1967). The model suggests that an individual's behaviour is driven by behavioural intentions. Behavioural intentions are seen as a function of an individual's attitude (positive or negative) toward the behaviour and their beliefs

surrounding the performance of the behaviour (pressure to perform the behaviour). Ajzen and Madden (1986) developed and re-evaluated the TRA model to construct the Theory of Planned Behaviour (TPB) which essentially added the factor of perceived behavioural control (a person's perceptions of their ability to perform a given behaviour).

Criticism levelled at this model has been its assumption that when someone forms an intention to act, they will be free to act without limitation. However, in practice they will be constrained by limited ability, time, environmental and organisational limits as well as unconscious habits (Harrison, Mullen and Green 1992; Ogden 2007). Ogden (2003) has suggested that the conclusions resulting from the application of the model were often true by definition, rather than by observation. This has been defended by Ajzen and Fishbein (2004) who note that to obtain any objective measures of some health-related behaviours, such as condom use, was virtually impossible. Additionally, there were significant time and monetary constraints that had to be overcome to collect objective measures. For these reasons, self-reporting was the preferred option.

Both models have been criticised because they are seen to be quantitative and reductionist in approach, which in turn has raised questions about their ability to predict attendance (Marks *et al.* 2005; Ogden 2007). Furthermore, the models have rarely included work related to people with LD, although the arguments are pertinent to the debate about screening up-take.

1.13. General findings of the predictive models

The models have suggested a number of indicators related to screening attendance in the general population such as information about breast cancer, perceived susceptibility and actual risk, such as family history (Champion, Sugg and Skinner 2003; Sutton *et al.* 1994; Wyper 1990). For women with LD, perceived susceptibility and actual risk, such as family history, may not be understood (Willis, Stagé and Sullivan 2009). Reasons for lower or non-participation in the general population were seen to be due to women who were either older, single, from lower socio-economic backgrounds, non-English

speaking, less educated or lesbians (Burack, Gurney and McDaniel 1998; Frazier, Jiles and Mayberry 1996; Fylan 1998; Marrazzo *et al.* 2000; Riain *et al.* 2001; Sheeran and Orbell 2000). Worry and fear about the procedure, the result and the negative image of the disease were also found to be useful predictors (Lostao *et al.* 2001). An application of the TRA model with women with LD was undertaken by Wicks (2007). She found that having information about the procedure was a factor in predicting up-take of cervical screening in women with LD. Although no studies have been undertaken using the models in breast screening in women with LD, fear of the procedure, embarrassment, and information were found to reduce uptake (Davies and Duff 2001; Isaacs 2006; McIlfatrick, Taggart and Truesdale-Kennedy 2011; Sullivan *et al.* 2003; Sullivan, Slack-Smith and Hussain 2004).

Cultural norms have also been found to predict non-participation in breast screening. Mexican women, for example, felt that exposing their breasts to health professionals was indecent and violated their cultural beliefs (Borrayo and Jenkins 2001). Working-class and Afro-American women were found to perceive cancer screening as a taboo, believing that by participating in screening they were 'courting cancer' (Balshem 1991; Russell and Shedd-Steele 2003). The review of the literature yielded no results for cultural norms in women with LD, although within the health professions there has been a suggestion that for some women, such as those with severe or profound LD and women with Down's syndrome, screening is inappropriate (Satge´ and Sasco 2002; Sullivan and Hussain 2004). Studies related to the women's own views of what influences them to participate and their views on breast screening would assist in this process.

1.14. Summary of chapter and study focus

The advent of industrialisation reduced people with LD from playing a full part in society and with this came the rise of institutionalisation. Social inclusion has tried to establish a lifestyle for people with LD that was no different to that of any other individual in society but this has not been as successful as was initially hoped, especially for women with LD. People with LD have the same entitlements as the general population within health policy and the law has both

acknowledged their health needs and their right to make their own decisions (where possible). People with LD may have acquired more autonomy but there has been a lack of foresight in the implementation of these new freedoms. Accessing GP services, for example, poses problems for people with LD since prior to their move into the community they never had to consider their own health because this was undertaken by those who supported them. The health of people with LD is now managed by GPs, paid-carers and health professionals who often have limited training about the health needs of this population, whilst day-to-day social care is delivered by numerous agencies and organisations who on the whole work independently of each other. Therefore the implementation of the NHS and Community Care Act 1990 and social inclusion may have inadvertently been more detrimental to people with LD than predicted.

Although there is a need for improvements in patient services in all areas of health care for people with LD, the government has set clear targets within health care policy to reduce cancer deaths. Normalisation of populations was used to explain screening programmes, in that women who attend for breast screening conform to the norm that for women aged 50 years or over attending breast screening is a way of managing the risk of breast cancer. Yet the lack of up-take of breast screening by women with LD is relevant to meeting government targets to reduce cancer. It therefore seemed timely to undertake a study that concentrated on this aspect. The predictive models of health belief gave many suggestions as to why women do not attend screening but little attention has been given to what influences participation of women with LD. A pertinent area to explore, given the different organisations that impacted on the women with LD, was what the experience of breast screening by these women was and what influenced their participation. This also reflected the principles of inclusive research in that the women's views would be heard.

1.15. Chapters

Having provided the background to the study, the following section will outline the structure of the thesis. Before doing this, the use of the first person within the thesis needs to be addressed. I have used the first person in all chapters

with the exception of Chapter 2. This is because the researcher should acknowledge within their project where they had personal involvement with the research (Horsburgh 2003). Chapter 2 presents an overview of the relevant literature and demonstrates a paucity of high quality research related to the topic area. From this review the research questions were formulated. The rationale for the chosen approach is given in Chapter 3, along with the choice of research design and analysis. In Chapters 4, 5 and 6, the findings from the study are documented whilst Chapter 7 gives a synthesis of the findings from the previous three chapters and discusses the findings in the context of the existing literature. Chapter 8 summarises the conclusions, proposes policy recommendations and suggests areas for future research.

Chapter 2:   The literature review

2.1.   Introduction

This chapter deals with the approach to the literature review that was undertaken to inform this study. It begins with an explanation of how the literature review was conducted. This is followed by the review of the literature on breast cancer and breast screening. The aims were to:

- Understand the incidence and prevalence of breast cancer in women with LD

- Explore and critique what had been written on breast cancer screening for women with LD

2.1.1.   The search strategy

To understand the state of knowledge in a particular field and identify the gaps within it, a literature review has to be undertaken (Carnwell and Daly 2001; Whittemore and Knafl 2005). Current thinking about literature reviews has suggested that they should meet the same standards as primary research in methodological rigour (Suri and Clarke 2009). Within the area of evidence-based medicine a clear hierarchy exists, with evidence with systematic reviews being at its apex (Dixon-Woods *et al.* 2006). Systematic reviews are considered the least biased and most transparent way to summarise the research evidence amongst the ever-expanding medical and health care literature (Moynihan 2004). This is because systematic reviews are seen to identify, describe, appraise and synthesise findings from individual studies by identifying studies according to an explicit search strategy. These are selected according to a defined inclusion and exclusion criteria and evaluated against consistent methodological standards (NHS Centre for Reviews and Dissemination 2001). A criticism of the systematic review process has been that the evidence has tended to focus on primary quantitative studies (Dixon-Woods *et al.* 2005). Inclusion of more diverse forms of evidence, including qualitative study designs, is now more common (Suri and Clarke 2009). In response to this, a more synthesised method of assessing such studies is now

undertaken. It was judged, therefore, to be important in this study not only to draw on primary empirical studies, but also to include a wider range of material such as 'expert opinions' to inform the review: for example, reports and editorials on educational materials (see section 2.5) was used to enhance the understanding of women with LD in relation to breast screening.

For researchers working within the LD field, the systematic review causes problems, in that the mainstay of the systematic review is the randomised control trial, but few people with LD tend to be involved in such trials (Davies and Duff 2001). Reasons for this often include small population numbers, problems with consent and having a definite diagnosis of a specific syndrome. Accordingly, this study chose an integrative review process. Integrative reviews summarise past research and draw overall conclusions from the body of literature on a particular topic. The body of literature that was compiled comprised all empirical studies that addressed related or identical hypotheses and met the same standards as primary research in regard to clarity, rigour, and replication (Beyea and Nichll 1998; Whittemore and Knafl 2005). Within this process the literature was still subjected to review, critique and synthesis (Torraco 2005). Although this review of the literature was not a systematic review, every attempt was been made to carry out this review systematically using the following principles:

- Identify the aims of the review

- Identify a search strategy to search for the literature

- Identify inclusion and exclusion criteria for selection of the literature

- Present a synthesis and summary of findings from the literature.

2.1.2. The aim of the review

The aim of the review was to explore the literature on cancer and breast screening in people with LD to identify key themes and gaps within current knowledge. To achieve this, careful consideration had to be given to the search terms. One problem identified at an early of the process was the different

terminology used to describe the LD population in the literature (see Chapter 1 for a fuller discussion). Previous knowledge of the area suggested that using only the terms 'learning disability' (in all its forms) and 'breast screening' would produce very little literature. Consequently secondary terms were drawn up to obtain a wider pool of literature to inform thinking. The terms were used in combination and were adjusted to suit the terminology of the database searched. All search terms used in the literature review are given below in Tables 1 and 2.

Table 1 highlights the terms used to identify terms associated with breast cancer and breast screening; Table 2 highlights the number of terms used to identify material on learning disability.

Table 1: Search terms used to identify material on Breast Cancer and Breast Screening

Main term	Secondary term
Breast screening	Mammography
Breast cancer	Mammogram
Breast cancer screening	Breast awareness
Cancer screening	

Table 2   Terms to identify material on Learning Disability

Main term
Intellectual disability (ies)
Developmental disability (ies)
Mental retardation
Learning disability (ies)
Down's syndrome
Cognitive impairment

To capture the grey literature and ensure total coverage of the data, searches of professional organisations, government organisations and special interest groups were undertaken (Smailes and Street 2011). Previous experience of undertaking work within the field also highlighted the need to undertake hand searches of journals (as not all journals are on line) alongside searching through books relating to LD on the University's library shelves. Networking through emails, conversations and conferences with other professionals and researchers in the field of LD and breast cancer also produced further material (McManus *et al.* 2006). To ensure continuous up-dating of the literature, alerting services were set up in a number of journals providing e-alerts, such as Blackwell Publishing. Due to the restrictions on the number of terms that can be entered into the alerting system, a truncated version of the key terms was used (see below, Table 3). These alerting systems were set for the duration of the PhD programme of study (2006–2011). Within these databases, it was also possible to perform individual searches within certain journals. Searches were performed biannually on the journals pertinent to the topic area, for example the British Journal of Learning Disabilities, using the truncated key terms to up-date and capture any new publications.

Table 3   The truncated terms used to set up the alert services for retrieving up-to-date material

Truncated key terms	Alerts service and search services
Breast screening	SpringerLink - continuous
Breast cancer	Blackwell Synergy - continuous
Learning disability (ies)	Zetoc 1993 – continuous
Intellectual disability (ies)	IngentaConnect - continuous
Mental retardation	ScienceDirect – continuous

The timeframe for the review was restricted to the last 10 years (January 2000 to May 2011), which accounted for the main period during which the NHSBCSP has been operational. However, some articles were included because they help establish the context of the study and go back as far as 1972. Although this suggests the literature review spans 28 years, this is not the case.

2.1.3. Undertaking the review

Inclusion criteria for participants included women with LD and, because they are often supported by other individuals, articles looking at paid and family-carers, community LD nurses, GP and health and allied-professionals were also reviewed. The types of studies that were considered for inclusion were as follows:

- Primary studies using quantitative and qualitative approaches

- Meta-analyses and systematic reviews

- Correspondence

The exclusion criteria extended to all studies not written in the English language and those on children with LD.

Once the searches had been conducted the titles and abstracts were screened for inclusion and eligibility using the criteria identified above. The findings from the electronic database review resulted in 42 papers and a decision was taken to include all of these articles to ensure that all the pertinent literature was reviewed. Also included in this review are papers that are not necessarily breast cancer related but are pertinent to the supporting work within the literature review, such as work on cervical screening and GPs working with people with LD. This material accounted for an additional 20 reference sources to give a final total of 62 papers, books and related material. A summary analysis of the literature on breast cancer and screening is presented in Table 4.

Table 4   Number of papers for LD and breast screening and breast cancer

LD and term	Status	Source of articles					Total
		Cinhl	**Amed**	**BNI**	**Med-line**	**Psych-lit**	
Breast screening	Retrieved	10	3	3	5	2	11
	Included	10	0	0	1	0	
	Repeats	0	3	3	3	2	
	Not relevant	0	0	0	1	0	
Breast cancer	Retrieved	7	3	17	40	8	11
	Included	3	0	4	4	0	
	Repeats	4	3	13	9	3	
	Not relevant	0	0	0	29	5	
Mammo-gram	Retrieved	9	1	1	3	3	8
	Included	5	0	0	1	2	
	Repeats	4	1	1	2	1	
	Not relevant	0	0	0	0	0	
Breast cancer screening	Retrieved	3	2	4	8	4	3
	Included	0	0	0	3	0	
	Repeats	3	2	4	3	4	
	Not relevant	0	0	0	2	0	
Cancer screening	Retrieved	27	4	6	15	8	9
	Included	5	1	0	2	1	
	Repeats	7	3	6	7	5	
	Not relevant	20	0	0	6	2	
Breast awareness	Retrieved	2	2	4	1	1	0
	Included	0	0	0	0	0	
	Repeats	2	2	4	1	1	
	Not relevant	0	0	0	0	0	
Total	-	-	-	-	-	-	42

All information was read, critiqued and summarised and from this a number of clear themes emerged:

- Incidence in cancer in people with LD

- Breast cancer screening in women with LD and Down's syndrome,

- Uptake of screening

- Intervention studies

- Appropriateness of breast screening

- Breast awareness

The review of the literature that is presented below has been delivered to experts within the field of breast screening and women with LD at local, national and international conferences. Two peer-reviewed papers and a book chapter have also been published (Willis, Kennedy and Kilbride 2008; Willis, Satgé and Sullivan 2008; Willis, Satgé and Sullivan 2010. The themes identified from the literature have informed the structure of this review. Work from British studies is initially considered before examining international studies around each theme.

A notable finding from the literature retrieved relating to breast cancer and breast screening was that most studies were located within North America, Scandinavia, France and the UK, although none were conducted in Scotland. Reasons for this concentration on cancer and breast cancer in the international work were not clear, although one suggestion might be the ease of access to population databases. Furthermore, having the facility of a database was seen as a strength compared to the smaller scale studies using opportunistic samples in the British work. In the UK, agencies such the Information Service Division (ISD) do not have a code for LD, although they do have codes for cancer, hence the lack of studies using this methodology and the poor status of knowledge on cancer incidence.

The justification for undertaking work in Scotland was twofold. First, there had been no studies identified in the area from Scotland. This was important

because health services in Scotland are organised differently from the rest of the UK. Additionally, as identified in the Chapter 1, breast screening in Scotland has different age parameters from the rest of the UK. Second, as the literature review revealed, there have been no published studies capturing the views of family-carers and only a few studies that capture the views of the women with LD and those supporting them through breast screening.

2.2. Incidence of cancer in the LD population

The evidence presented in this literature review revealed that the incidence and type of cancer in the LD population differed depending on where the work was undertaken and the aetiology (cause of a certain condition or disease) of LD. Evidence from the UK comes from a series of longitudinal studies, looking at cause of death reported in hospital records over a 65-year period (1930–1995) of residents with LD of the Stoke Park group of hospitals (Carter and Jancar 1983; Cooke 1997; Jancar and Jancar 1977; Jancar 1990). Using post-mortem data over a forty-year period, Jancar and Jancar (1977) found that there had been 1,125 deaths in people with LD and of those, 81 (7.2%) had been due to cancer. The authors stated that the incidence of cancer was 8.7% (51) in females compared to 5.6% (30) in males, and that the female death rate was higher than in the population in the community (but they do not give any percentages for this). They also commented that the overall rate for cancer in the LD population (7.2%) was lower than the general population while the incidence of deaths in females with LD from cancer was higher than in females in the general population.

Carter and Jancar (1983) examined causes of death and mortality from hospital records of patients with LD at Stoke Park hospitals group between 1930 and 1980. Of the 1,383 deaths in this period, 103 were from cancer (7.5%). Deaths from cancer also increased from under 4% to over 12% during the period studied. The authors suggested that this increase was due to the increased longevity of the population which had risen from 56.6 years (in Jancar and Jancar 1977) to 65 years in this study. Jancar (1990) reported findings for the period 1976 to 1985 finding the total number of deaths to be 302 (173 women with LD, 129 men with LD). Fifty-three deaths (17.5%) (34 women, 19 men)

were due to cancer and it was noted that the percentage of deaths for all types of cancer had showed a marked increase compared with the previous four decades, rising from under 2% in the period 1935–1940 to 20% in 1981–1985. However, Cooke (1997) reported an overall incidence of death from cancer from 1986–1995 of 13.6% in people with LD compared to 26% in the general population.

These studies generally report an increase in the number of deaths from all types of cancer but a lower overall incidence of cancer in the LD population compared to the general population. However, no diagnostic criteria or age and incidence were documented, making comparisons with other studies difficult. Despite the known inaccuracies of hospital records, such as poor documentation (Hogg, Northfield and Turnbull 2001) similar trends to that of the Stoke Park group were found in other British work. Cole *et al.* (1994) used post-mortem findings and noted lower incidence, finding 4 out of 60 deaths (6.6%) resulted from cancer in people with LD. Puri *et al.* (1995) examined principle cause of death over a 10-year period and found that in 325 deaths in people with LD, cancer was attributed to 15.4% (50) of these cases. Although claiming cancer had increased, no evidence was cited to support this. As with all the British studies, no details were given about the composition of their hospital population or standardised mortality ratio, so meaningful comparisons across studies cannot be made.

International studies have enabled stronger comparisons to be made since they have linked population cohort records with records from cancer and disability registries. These studies did not identify differences in the incidence of cancer in people with LD compared to the general population. In Finland, Patja *et al.* (2001) studied 2173 people with LD from 1967-1997 and observed that the number of cancers in the cohort (173/2173) was close to what was expected in this population, giving a standardised incidence ratio (SIR) = 0.9, 95% confidence interval (95% CI) = 0.8–1.0. Sullivan *et al.* (2004) reported that out of 2,370 cases in Australia, a lower incidence of cancer was observed among people with LD compared to the general population. This was divided by sex: in males 103 cancers were observed compared to an expected 349.2 cases (UIR (unadjusted incidence ratio) = 0.29, 95%CI= 0.24-0.36); in females 97 cancers

were observed compared to an expected 215.8 cases (UIR = 0.45, 95%CI= 0.36-0.55). This finding was reported to be the result of small numbers in the sample. When ratios were standardised by a 5-year age group, the effect was reduced and the cancer risk was found to be similar to the general population (male SIR = 1.14, 95%CI= 0.93-1.38; female SIR = 1.01, 95%CI= 0.82-1.23). Neither study reported any potential hidden population (i.e. those who would not be on disability register) or adjusted for missed diagnoses. It was felt that the difference in data collection and cultural differences would account for the differences in findings from the British studies.

Aetiology and severity of LD have been thought to contribute to the difference in incidence of cancer in people with LD. Aetiology (cause of a certain disease or condition) is dominated by work on Down's syndrome (DS) because DS is the most frequently identified cause of LD (Yang, Rasmussen and Friedman 2002). Genetic and microbiological work has suggested over expression of the genes on chromosome 21 (the chromosome abnormality responsible for DS) has a negative effect on tumour onset and progression (Benard, Beron-Gaillard and Satgé 2005; Zorick et al. 2001). Trisomy-21 fibroblasts (a specific cell type) have been shown to divide more slowly in culture than normal fibroblasts giving less opportunity for replication errors in genes involved in tumorigenesis [renewal] (Schneider and Epstein 1972; Segal and McCoy 1974). Furthermore trisomy-21 cells are more prone to apoptosis (cell-death) than non-trisomic cells if they sustain additional mutations (Sawa 1999). Other evidence has found that tumour presentation in DS is linked to the stroma (cellular matter). Where the stroma is well differentiated, for example in solid tumours such as breast cancer, the stroma is thought to offer protection whereas where the stroma is less differentiated, such as in leukaemia, there is less protection (Hasle, Clemmensen and Mikkelsen 2000; Satgé et al. 1998).

Alongside aetiology, severity of the LD has also been discussed within the literature. Many people with profound and severe LD have shorter life expectancy (not living past their thirties) due to their complex health needs. Consequently they may not live long enough for cancer to develop or be recognised (Hogg, Northfield and Turnbull 2001). In those with more moderate

to mild LD, cancer is thought to be increasing (although no figures are given) due to more exposure to shops selling tobacco and alcohol. Lifestyle factors such as poor diet, smoking and weight gain play a part (Baxter and Bradley 2008; Emerson *et al.* 2005; Mencap 2004; Stanish *et al.* 2006).

The most common cancers in the general population are breast, lung, large bowel (colorectal) and prostate, which account for over half (54%) of all new cases (Cancer Research UK 2010).The types of cancer found in the learning disabled population is a little clearer than for general cancer incidence, and reveals a very different profile from that found within the general population. Both British and international studies highlight the higher incidence of gastro-intestinal cancer among people with LD compared to the general population. In the UK, Jancar and Jancar (1977) reported that of 1,125 deaths in people with LD in Stoke Park hospital between 1936-1970 found that 58% of cancer deaths were from gastrointestinal cancer compared with 25% in the general population. This was supported by Jancar (1990) who noted 58.5% (31/52 patients with LD who died of cancer) died from gastrointestinal cancer. In Australia, Sullivan *et al.* (2004) noted the increased incidence of stomach cancer in males with LD (SIR = 3.19 95% CI = 1.29-6.59), while a Dutch study (Bohmer *et al.* 1997a) reported from a population of 1,546 people with LD that there was a higher incidence with a standardised morbidity ratio (SMR) in the LD population of 2.9 (95% CI = 1.8-4.1; P < 0.001) compared to an expected incidence for oesophageal cancer based on age-related incidence in the general population of 7.0.

Finnish work (Patja *et al.* 2001) reported no difference in incidence between the LD or the general population, reporting data for the LD population (observed 53, expected 53.5 SIR= 1.2 95% CI =0.9-1.5). Infection by *Helicobacter pylori* (H Pylori) has been linked to gastrointestinal cancers in people with LD and is a common problem in the LD population (Scheepers *et al.* 2000; Duff, Scheepers and Cooper 2001). Bohmer *et al.* (1997b) have found *H pylori* infection to vary in two Dutch institutions for people with LD. Of the 338 people with LD, 82.5% (280 people) had *H pylori* whilst of the 254 employees, 27.2% (69) were infected with the *H pylori*.

Similarly, international work on leukaemia has consistently reported higher incidences in people with DS particularly in children with DS compared to the general population. Australian work by Sullivan *et al.* (2007) found from a study of 1298 people with DS, that the incidence of leukaemia was 61.6 times higher in children with DS aged 0-4 than the general population (95% CI =31.84-107.62). A French review of papers citing tumours in people with DS noted an overall 20-fold excess of leukaemia in people with DS compared to the general population (Satgé *et al.* 1998). Dutch work identified that out of 60 people with DS and cancer there were 36 who had leukaemia whereas two people with DS and leukaemia were expected (SIR= 17.6 95% CI 12.4-24.4) (Hasle, Clemmensen and Mikkelsen 2000).

In summary, the main findings of this section were that the cancer incidence was seen to be lower than that found within the general population with the exception of gastrointestinal cancer. Incidence of cancer also differed within the LD population with people with DS seen has having protective factors, with the exception of leukaemia. Other factors may contribute to the incidence of cancers, such as the severity of LD.

2.2.1.   Breast cancer in women with learning disabilities

This section will review work on breast cancer in women with LD from the British and international perspectives. Breast cancer in women with DS is considered separately as more work has been conducted on this group of women with LD. Overall, the findings suggest that incidence of breast cancer is similar if not lower for women with LD than women in the general population and lower still in women with DS.

British longitudinal studies undertaken by the Stoke Park Hospital group used cause of death documented in hospital records over a 65-year period (1930–1995) (Jancar and Jancar 1977; Jancar 1990; Cooke 1997). Findings were reported in separate papers, using different time periods and different sample sizes. In the first study, the records of 870 females with LD were examined between 1936 and 1975; of these women, 13 (26% of female cancer deaths in this population) died from breast cancer (Jancar and Jancar 1977). Jancar

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(1990) reported findings for the period 1976–1985 finding the total number of deaths from cancer in women with LD to be 34, of which five deaths (15%) were due to breast cancer. The review of the last period, 1986–1995, reported 29 cancer deaths in both sexes with LD from cancer but only one female death due to breast cancer (Cooke 1997). Overall, these studies have suggested that the incidence of breast cancer was lower than the general population. A criticism of the studies was that the work did not take into account the ageing and changing character of the population (those with severe/profound learning disability tended to remain in the hospital) and did not provide age-stratifications (which would have been useful in determining whether the cancer mortality was lower than suggested).

In contrast, international studies have provided a different perspective from the British studies, in that more have concentrated specifically on breast cancer. A more robust study was conducted by Patja *et al.* (2001) in Finland that linked the records of 1,083 women with LD from an on-going population survey which had previously identified and tested individuals to determine the severity of their LD, to the National Cancer Registry for the period 1967–1997. It was expected that 25.8 breast cancers would be observed but the findings showed only 23 breast cancers in women with LD, giving a SIR of 0.9 (CI 95%: 0.6-1.3) which was similar to that in the general population. In the article, Patja *et al.* (2001) noted the limitations within the study, commenting on the small sample size for all cancers in the study (2,173) which may have influenced the SIRs for rare cancers. Apart from cultural differences, Hogg, Northfield and Turnbull (2001) suggested that the differences between the British and Finnish findings were due to the different population bases, time span and the data used. Comparisons between the studies could not be made due to the differences in data collection methods and the lack of SIR in the British studies.

The above analyses did not specifically concentrate on breast cancer in women with LD, whereas work in Western Australia and unpublished research from France has done so. Australian work identified 2,370 women with LD diagnosed with breast cancer during the period 1982–2000 by linking individual records of women with LD to the Western Australia Cancer Registry and the Mammography Screening Registry (Sullivan *et al.* 2003; Sullivan and Hussain

2004). All participants were identified through the Western Australia Disability Services database and consisted of women with LD who were 25 years of age or more. Findings revealed that the incidence of breast cancer in women with LD was lower (64.0 per 100,000 person-years) than the general population (146.7 per 100,000 person-years). Of the 2,370 women with LD on the cancer registry, only 20 had been diagnosed with breast cancer compared to 45 incidences in the general population over the same time period, with small numbers preventing further detailed analysis (Sullivan *et al.* 2003). In this study, data linkage was seen to have a 90% success rate as the authors acknowledged incomplete/missing data.

In France, unpublished work revealed that from 515 incidents of consecutive invasive breast cancers, 11 (2 % of all cases) were from patients with LD and this was seen to be comparable to the prevalence of breast cancer in the general population (Satgé 2009).

The lower incidence reported in all the studies above has been linked to reduced uptake of breast screening; lower detection could be artificially masking breast cancer in this group of women with LD (Patja *et al.* 2001; Sullivan *et al.* 2003). Although breast cancer has an inheritable component in 5-10% of cases, only one (American) study addressing this issue was retrieved. This paper was a single case study (i.e. one woman with LD) and described the process of providing BRCA1 testing (genetic testing) to a woman with 'limited mental capacity' and documented the psychological distress this caused (Schneider, Kieffer and Patenaude 2000). A criticism of this paper was that no measurement of capacity had been undertaken or any documented collaborative working with specialists in LD. French work has noted that 45 women with DS who had a family history of breast cancer had an 'elevated risk of breast cancer', compared to those women with DS with no family history who had a 'very low risk' (Satgé *et al.* 2008).

In summary, although incidence of breast cancer in women with LD was generally reported as being lower than among the general population, some authors have reported incidence to be the same as in the general population. These findings must be treated with caution because not all studies specifically

had breast cancer as the main focus of their work. Furthermore, the reported low up-take of screening services may also contribute to the lower reported incidence of breast cancer. Few studies were identified that concentrated on hereditary breast cancer in this population.

2.2.2. Cancer and women with Down's syndrome

Genetic work on DS has provided more detail on the protective factors of DS in breast cancer. In a French study by Benard, Beron-Gaillard and Satgé (2005), breast cancer cell lines showed significant growth inhibition (30%) when fibroblasts (specific type of cells) from a patient with DS were cultured onto an extra cellular matter. They concluded that this explained why stroma-rich tumours (solid tumours such as breast cancer) are very rarely found in people with DS. Single-minded 2 (SIM2) are part of the chromosome thought to contribute to the aetiology of DS, and have been found to contain protective factors from breast cancer. An American study working at the cellular level has identified that SIM2 and SIM2s may have tumor suppressor activity in invasive breast cancer cells (Kwak *et al.* 2007). Work on blood serum in Brazil by Zorick *et al.* (2001) found elevated levels of endostatin (a substance thought to stop new growth) in serum taken from people with DS. Through their work they noted that COL18A1 (a cellular substance in the endostatin) may explain the relative decrease in incidence of solid tissue tumours observed in people with DS. This was because endostatin inhibited tumour growth. Both these studies were linked to reduced incidence and mortality of breast cancer among women with DS.

The evidence for reduced breast cancer in women with DS has more commonly come from epidemiological studies. Three British studies reported on cancer in people with DS alongside other health issues. Jancar and Jancar (1977) found that of the 115 patients with DS who died over the 40-year period, none died from cancer; they report that they would expect 8 cancer deaths in a series of 115 deaths. A cohort study of 1,425 persons with DS and of their parents (447 mothers, 435 fathers) and siblings (1,176) was drawn from the records of collaborating genetic units in England and Scotland (Hermon *et al.* 2001). Records from 1959–1990 were flagged and followed-up through the National

Health Service Central Registers. Results from this study noted only one death from breast cancer in the data from people with DS. The authors noted the difficulties of tracing and coverage, especially when individuals reached the age of 85 as death or the incidence of cancer after this age was not always recorded on the flagged record.

The other study (Goldacre *et al.* 2004), again a cohort study, linked abstracts of hospital and death records in the former Oxford health region between 1963 and 1999. A cohort of 1,453 people with DS and a cohort of 460,000 people without LD with other conditions were used for comparison. The main outcomes did not include breast cancer because analysis showed only one case or no cases in the cohort. The authors also noted that the dataset was not complete, as patients who moved out of the area or those who were treated in hospitals outside the region were not included.

More work has been undertaken by international researchers who have used a population database method of linking up with cancer registries. Hasle, Clemmensen and Mikkelsen (2000) identified 2,814 individuals with DS from the cytogenetic register in Denmark, from the period from 1961 to 1994. This data was linked to the Danish Cancer Registry where 60 individuals with DS were identified as having cancer. From these 60 individuals, 7.3 cases of breast cancer were expected, but none were found (p=0.0007). Similarly, Satgé and Sasco (2002) conducted a national epidemiological study on mortality in France in people with DS over 24 years and found only five deaths from breast cancer in women with DS (68.98 expected; Fisher test: P<0.00005) in a population of 6,898.

A Finnish cohort of 3,581 persons with DS was identified from a National Registry of Finnish people with LD and was linked to The Finnish Cancer Registry (Patja *et al.* 2006). These databases were seen to be 99% complete as suggested by other surveys (Korhonen 2002). Data were collected between 1978 and 1986 and followed-up for cancer incidence until 2002. Among the 1,693 women with DS, only six breast cancers were reported. Hill *et al.* (2003) explored cancer incidences and mortality in people with DS in a joint Swedish and Danish study. They noted that three cases of breast cancer were observed

from the combined cohort of 2,250 females with DS; two deaths from breast cancer were in Sweden and one in Denmark. Hill identified her population sample from the Swedish Inpatient Register and the Danish Hospital Discharge Register. She used individual hospitalisation records linked to the Swedish and Danish populations, migration, cancer incidence, and mortality registries using national registration numbers. As age of cancer diagnosis is only reported as being greater than 20 years age, trends cannot be ascertained meaning comparisons with other studies cannot be made.

In the USA, a large epidemiological study reviewed 17,897 death certificates of people with DS collected between 1983–1997 from the US Centres for Disease Control and Prevention National Centres for Health Statistics (Yang, Rasmussen and Friedman 2002). From this data only 25 breast cancer deaths were found in women with DS. However, the authors comment on the inaccurate and incomplete data contained within the death certificates and note the paucity of cancer reported in them. Despite this, the findings were consistent with those of Hasle, Clemmensen and Mikkelsen (2000), although differed from Hill *et al.* (2003), possibly because of differences in the source population (deaths only) and the methods of analysis.

Sullivan *et al.* (2007) identified individuals with DS through records of the Disability Services Commission of Western Australia which yielded 1,442 people. This data was then linked to the Western Australian Cancer Registry and reduced the total to 1,298. Although 247 women with DS aged 25+ years were identified, they found no cases of breast cancer compared with an expected incidence of 4.4. Personal communication reveals only one study that focused specifically on breast cancer and DS in France, indicating a 14-fold decreased mortality from breast cancer with only five deaths observed where 68.98 (p < 0.0005) were expected from a population of 6,898 people with DS (Satgé 2001).

In contrast, other conditions involving a component of LD have been found to increase the risk of breast cancer. An American study found that in a sample of 21 women with Cowden's disease 10 out of 21 women had breast cancer, whilst the other 11 women who did not have breast cancer had other pre-

cancerous conditions such as fibroadenomas and malformations of nipples and areolae [the colored skin surrounding the nipple] (Brownstein, Wolf and Bikowski 1978). The conclusions from this study suggested that women with Cowden's disease had a higher risk of developing breast cancer and those dermatologic lesions were good indicators to the development of a breast malignancy. In America, mortality from breast cancer in women with cerebral palsy was found to be three times that of the general population, suggesting poorer detection and or treatment (Strauss, Cable and Shavelle 1999). The risk of breast cancer in a cohort of 304 women with type 1 neurofibro-matosis (NF1) aged 20 years or over in America was found to be high. These women were assessed during the period 1975–2005, and 14 cases of breast cancers were identified giving a SIR of 3.5 (95% CI 1.9 to 5.9), with six breast cancers occurring in women in their 40s, giving a SIR of 4.9 (95% CI 2.4 to 8.8). Findings from this study concluded that women with NF1 aged less than 50 years have a fivefold risk of breast cancer and recommended that they be considered for mammography from 40 years of age (Sharif *et al.* 2007).

In summary, the incidence of breast cancer in women with DS is thought to have a genetic component. Population studies looking at cancer incidence have consistently reported breast cancer in women with DS as being lower than expected for the population. Further work in the area of genetics is needed in order to fully understand the links between breast cancer and DS.

Overall summary: Within the last five years, the literature on cancer in people with LD has expanded. It suggests a different cancer profile from that found in the general population. Much of the focus has been on breast cancer in women with DS because of the protective properties this syndrome may possess. Women with other syndromes such as Cowden's disease were identified as being at greater risk of developing the disease. The international work was seen as more robust than the British work due to the data linkage facilities, and suggests that the incidence of breast cancer in the British population is relatively unknown. Further work in this area is necessary to ascertain the incidence in the UK. The risk of breast cancer in women with LD (especially with DS) is thought to be comparable if not lower than women in the general population. However, some authors have suggested the incidence of breast

cancer among women with LD may be being masked by the low up-take of breast cancer screening. Further research is needed to unravel whether low incidence of breast cancer is due to immunity from breast cancer or due to lack of detection resulting from low up-take of breast screening. In addition, reduced exposure to environmental factors that contribute to cancer risk, such as tobacco, alcohol, and certain occupational exposures, cannot be ruled out as these factors may increase as more people with LD come to live in the community.

2.3.   Up-take of breast cancer screening in women with LD

The up-take of breast cancer screening in women with LD has been found to be lower than women in the general population. The Disability Rights Commission (2006) analysed data from GP practices on the up-take of screening in Wales, determining that up-take rates for breast screening was 26% in people with disabilities (including LD) compared with 71% in the practices overall. Actual figures such as the population or sample are not reported. The White Paper *Valuing People* (Department of Health [DoH] 2001a) noted that up-take of screening services in people with LD was poor, although no figures are given to support what the up-take is. Poor up-take is comparable to women from other minority groups such as women with physical disabilities or ethnic backgrounds (Haitt *et al.* 2001; Mele *et al.* 2005; Nosek and Howland 1997).

Three British studies reported low up-take of breast screening in women with LD. Pehl and Hunt (2004) observed low up-take although refer to earlier work that was unpublished in their article but do not give any details about the study such as the sample used, hence evaluation of the research could not be presented. Piachaud, Rohde and Pasupathy (1998) and Piachaud and Rohde (1998) reported on a postal health survey targeting women with DS. Twenty-seven women were contacted and 20 responded; their ages were between 18 and 57 years. Two of the 20 respondents (both in their 30's) reported attending for breast screening but no comment was made on the rarity of women in their 30's going for screening; younger women usually only attend mammography to check an existing lump or because of a family history of breast cancer. In a letter to the Editor, Piachaud and Rohde (1998) concluded

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that low up-take was the norm in this population. However, these findings are difficult to support because the number of women with DS eligible for breast screening in the sample (those women aged 50 and over) was not documented.

The final British study (Djuretic *et al.* 1999) reviewed screening records (cervical and breast) from women on the LD register in Brent and Harrow and compared this data with the records of the general population. They identified 336 women with LD (age range 20–64) and found that 32 women out of 73 (43%) eligible women had attended breast screening. It is presumed that the 32 women were in fact eligible for breast screening. The authors also did not say whether there was complete coverage in the disability register. In all the British studies, attendance was noted as being low, but few reasons were given as to why this might have been the case.

Internationally, only one study reporting low up-take was found. This was an Australian study that utilised record linkage from the cancer and disability registries (Sullivan *et al.* 2003, 2004; Sullivan and Hussain 2004). Records revealed 674 women with LD were eligible for screening but only 380 of these could be linked to the mammography database. Of the 380 women with LD, 154 had a screening record, of whom 132 had undergone breast screening. The remaining 22 had declined the invitation. Of the 132 women with LD who had undergone breast screening, six had been diagnosed with breast cancer from their screening visit. Further analysis using univariate and multivariate analysis revealed that women with severe LD, epilepsy, cerebral palsy or living in institutional care, were less likely to be screened, while marital status and living in a rural area were better predictors of attendance at screening. The reasons for attendance or non-attendance were consistent with findings within the work on the predictive models. The authors acknowledged that small numbers in the work and the incompleteness of the databases prevented further analysis.

A number of studies reported higher up-take of breast screening, and again more studies have been completed in the UK than internationally. In the UK, Davies and Duff (2001) sent postal questionnaires to 99 women identified as having a LD who were living in group homes within a single community care

provider. Among the 58 returns (59% response rate) 30 women reported receiving an invitation to breast screening. From this, 27 out of the 30 women (90%) said they had attended breast screening, which was higher than usually seen within the general population. No direct reasons for the higher level of up-take were given, although this figure assumed that those women who received an invitation were also the women who reported attending for breast screening. This may not necessarily have been the case.

Davies and Duff (2001) cited a number of weaknesses in the study and acknowledged that carers may have played a role in completing the questionnaire. Therefore there could have been a response bias as no information was collected about whether the carers knew or had accompanied the women to breast screening and the women themselves may have had poor recall of the event. A number of observations were also reported. For example, although up-take was higher, 23% (13) of the women reported being given no explanation about the procedure and questions were raised about informed consent. Although all the women with LD were registered with a GP, 31% (18) reported not receiving an invitation which the authors suggested was due to GPs removing them from the screening list on the grounds that they felt they were inappropriate for screening (which was the practice at the time). The authors commented that there was a need for additional training about the health needs of women with LD to prevent diagnostic overshadowing (seeing the disability not the presenting problem).

Another British study undertook an audit of cervical and breast screening records of women with moderate to severe LD who were aged 20–64 years and were in contact with NHS LD services (Biswas *et al.* 2005). The audit revealed that 235 eligible women were known to the service, but only 160 were traceable. Reasons for not being able to trace the women included 23% (54) who were no longer registered with a GP or their current address was unknown. From the 160 women, 30% (48) were found to be eligible for breast screening. The local mammography unit confirmed that 77% (37/48) had attended for breast screening. Although the study originally sought to give counselling to non-attendees, it was decided that the Breast Screening Unit would run a 'catch up programme' (details of this were not specified) for the women with the help

of the community LD nurse. While 77% attendance at breast screening appears to be high, up-take only accounted for those in contact with LD services and not those who were unknown to the service. Furthermore, nothing is documented about whether the women specifically chose not to attend, the reasons given for non-attendance, whether any of the women took part in the catch-up programme or what format the catch-up took.

Gesualdi (2006) [American] surveyed 208 women with LD in different residential settings about attendance at breast and cervical screening and found percentages attending for mammography (which begins at 40 years of age in America) and clinical breast examination (which is performed annually), were similar to the general population. The differences found here from the findings from work in the UK may be due to having to pay for medical care in America. Of 208 women with LD, 93% in intermediate care (a definition of this was not given), 85% in group homes, 86% in supported living and 75% in family homes, had undergone a clinical breast examination in the last year. Of the 139 women with LD identified, 86% in intermediate care, 87% in group homes, 63% in supported living and 78% in family homes, had undergone a mammogram within the last 2 years. As only percentages are reported and little detail is given about how the data were collected or how many women with LD were eligible, or lived in each residential setting, findings are difficult to compare or interpret thoroughly.

The literature surveyed in this section has suggested that low up-take of breast cancer screening in women with LD is the norm but for the most part it is unable to identify what prevents the women from participating. This suggests that the women have therefore not been normalised into attending screening. The barriers reported in these studies were similar to those found in the work on the predictive models which suggests that women with LD have similar reservations about breast screening as women in the general population.   Much of the work is in the area of LD has been based on small-scale surveys with only one data-linkage study, whilst studies noting higher up-take are difficult to compare due to flawed reporting.

2.3.1. Barriers to attending breast screening

This section will look at some of the barriers that prevent women with LD attending breast screening. A number of papers in this section reported few details about the work undertaken which prevented a thorough review being performed. Evidence of barriers to breast screening was broken down into three themes: the views of the women themselves; the people who supported the women; and anecdotal references within the papers.

2.3.2. British work on barriers to attending breast screening

If women with LD are to be normalised in to screening they too should be asked about what prevents them from attending breast screening. Yet only three studies, two British and the other Canadian, have asked women with LD about what prevents them participating in breast screening and all but one are unpublished. In the UK, Pehl (1999), cited in Pehl and Hunt (2004), could not be sourced as it was an internal document and so could not be reviewed. A conference presentation by Proulx *et al.* (2008) reported interviewing 12 women with LD, five agency representatives and 25 staff from screening centres. The interviews focussed on obstacles, facilitating factors and possible improvements at each entry point of the programme. Obstacles highlighted were complex appointment processes, accessing mail, negative staff attitudes and unfamiliarity of people and place. Facilitators to screening were seen as having more appropriate, tailored information, more positive attitudes towards people with LD and better preparation for the procedure. Contact was established with the author but further details were not made available.

The only published paper was from Northern Ireland, and involved 19 women with borderline to moderate LD (aged between 31–69 years of age) who had received mammography within the last year (Truesdale-Kennedy, Taggart and McIlfatrick 2011). Four focus groups were undertaken and the women in each group were asked their opinions on the following topics: risk factors and signs and symptoms of breast cancer, their experience of mammography and barriers to participation in screening. The findings revealed that the women had poor knowledge about breast cancer or breast awareness. The experience of

undergoing mammography was found to induce anxiety, stress and pain, and without a thorough explanation these feelings were exacerbated. Despite this, the women reported positive feelings about having the mammogram and this was facilitated by support from friendly staff.

The main barriers reported by the women were fear of the procedure and the potential outcome (having cancer diagnosed) as well as embarrassment at having to remove their clothes. Facilitators to attending breast screening were information and emotional support. The authors highlighted the limitations of the study, noting the small sample size and inability to generalise from their findings. However, no comment was made about the three women below the age for mammography or why they were referred for breast screening, as this may have impacted on their experience and knowledge. Furthermore, it is presumed that none of the women were diagnosed with breast cancer. The authors recommended that future work should concentrate on how women make the decisions and exploring the reasons offered by those women who refused to attend for their non-participation.

Work looking at health and social care professionals has mainly been undertaken in the UK. A study carried out in Northern Ireland looked at different health professionals and paid-carers, and published two papers on their views. The first involved primary healthcare staff (n= 9) and breast care staff (n= 9) supporting women with LD to access breast screening (McIlfatrick, Taggart and Truesdale-Kennedy 2011). The investigators used a focus group and 14 telephone interviews. The participants discussed their views on the following topics: the understanding of the risk factors of breast cancer; barriers and enhancers to participation in screening; the experiences of supporting women with LD to attend breast screening; and how to help women with LD to access breast screening. The findings showed good knowledge about the risk factors in breast screening. Barriers identified included cognitive functioning, literacy problems, consent issues and physical health (mobility problems) as well as transport, timing of appointments, and staff and parental attitudes.

The participants were unanimous that the women should receive breast screening and acknowledged their role in providing health promotion and

education to the women. Facilitating attendance at breast screening was identified as having someone to accompany the women and afternoon appointments due to travel considerations. Improvements were also called for in terms of inter-professional working and awareness of the LD population within the GP catchment areas. Unlike the rest of the UK, the authors alluded to GPs still scrutinising screening lists prior to invitation letters being sent out. This study gave an insight into the role of the healthcare professionals and views about breast screening in women with LD. It also highlighted the differences within the organisation of health care throughout the UK for people with LD: within Scotland, for example, speech and language therapists and education workers would also be involved in preparing women for procedures.

In the second study, Taggart, Truesdale-Kennedy and McIlfatrick (2011) organised six focus groups, three with 16 Community Learning Disability Nurses (CLDN) and three with 13 Residential Workers selected from across a range of supported housing and residential accommodation in Northern Ireland. The topics used in the focus groups were the same as in the previous study discussed above (McIlfatrick, Taggart and Truesdale-Kennedy 2011). Most participants were found to be informed about the risk factors associated with breast cancer although knowledge was poorer within the Residential Workers. Most, but not all, of the CLDNs questioned were aware of appropriate breast screening literature, in contrast to only a few Residential Workers, most of whom were not aware of appropriate literature on breast screening. When the letter of invitation was received by the women, the CLDNs and Residential Workers both assisted them to understand the letter. Part of the role of the CLDN was to assist the women to attend breast screening and offer information to the women's family and paid-carers about screening as well as support the breast screening nurses who had clients with LD.

This study disclosed similar barriers to those found in the previous paper (McIlfatrick, Taggart and Truesdale-Kennedy 2011) with the addition of appointment clashes with day-time activities, family-carers and mental health problems. The residential workers also raised the issue of resources. There was a perception within both groups that breast screening was not well promoted for women with LD. The need to develop a range of health education

material specifically tailored to this client group, in the form of leaflets, booklets and videos/DVDs, was identified. Some participants highlighted the necessity of having educational sessions developed for women with LD and their carers, as well as breast screening clinics. There was a consensus on the need for better multi-disciplinary working and education and training on issues relating to LD.

This research provided a valuable insight into CLDN and residential workers' views and understanding of breast screening in women with LD. It must be noted, however, that three of the residential workers also held nursing roles, so their perspectives may have been different from those without formal nurse training. The need for multi-disciplinary working and training echoed findings by Tuffery-Wijne *et al.* (2009) on cancer in people with LD.

Other British research has looked at primary care providers and suggested that they may inadvertently constitute a barrier. Stein (2000) asked 64 GP practices to take part in a survey on health in people with LD and 48 agreed to participate. One question specifically related to breast screening asked GPs a hypothetical question about what they would do if a woman with LD eligible for breast screening had not attended. Of the 45 GPs who answered the question, 28 said they would write or offer a consultation and four said they would leave it be. Thirteen answered 'other', including stating that they would discuss when next seen (4), and discussing with the support worker or carer (5). Although not representative of all GPs, Stein (2000) noted that discussions about such health matters were a rarity. As nulliparity and obesity are risks factors for breast cancer, the idea of 'leaving it be' was seen as contentious. Many women with LD often have no children and are obese.

2.3.3.   International work on barriers to attending breast screening

International research has also focused on paid-carers. Australian work using four focus groups with a total of 30 paid-carers from different hostel settings (numbers used in each focus group were not given) identified a number of barriers including standing during the procedure, mammographers' attitudes,

pain from the procedure, attitudes of paid-carers to screening and poor knowledge among the women with LD (Sullivan, Slack-Smith and Hussain, 2004). Factors facilitating screening up-take included being accompanied by the social trainer and the proximity of the clinic. This study gave a useful insight into potential barriers although it did not represent all care settings since the voices of family carers were absent. Furthermore, some aspects seen as barriers, such as the attitude of the mammographer, are hard to anticipate. Interviews with women with LD were planned; however, the clinicians attached to the study felt that only women with mild disability should be interviewed. The reasons given were that women with moderate or severe disability would need assistance from their social trainer and so their views, not those of the women, would be recorded (Sullivan, Slack-Smith and Hussain 2004).

A French study used standardised telephone interviews with GPs to ascertain breast cancer screening (BCS) practices with women with physical and mental (defined as intellectual or psychological) disabilities (Verger *et al.* 2005). From a total of 1,200 GPs, 1,076 (89.7%) were eligible (recruitment criteria excluded, for example, GPs about to retire) and 600 (55.8%) agreed to participate. The questions within the survey asked about how often they performed BCS for patients with physical or mental impairments, whether they felt uneasiness in providing care and about their own personal experience of disability. Overall, 27.3% (n=161) of GPs reported inadequate breast cancer screening practices due to feeling uncomfortable when treating people with disabilities, lack of assistance and communication difficulties. Limitations of the study were acknowledged by the authors. For example, the poor response rate meant the survey was not representative of all GPs; evidence was based on self-reporting rather than direct observation; and discriminatory practice may not have been recognised. Within the literature, the lack of GPs' knowledge about the health needs of people with LD and the need for more training were raised by several authors (Ng and Li 2003; Phillips *et al.* 2004; Stanley 1998).

The work of Verger *et al.* (2005) has paralleled research conducted on minority groups within the general population and hints at one area where equality of treatment may not have occurred. American research on 36 and 23 cognitively compromised older women identified by doctors' or daughters'

recommendations, found perceived risk of breast cancer, habit, functional status, or personal history of breast disease, as being important factors in whether they participated in breast screening (Salazar and de Moor 1995; Schonberg *et al.* 2006;). Afro-American women (n=2,068) reported that doctors tended not to recommend that they participate in screening (Frazier *et al.* 1996). Shortened life expectancy and impaired cognitive functioning were factors on which 34 American clinicians based their judgement about screening participation when advising older women in the general population (Wolfson *et al.* 2001). Similarly, within the LD literature, people with LD in both the USA and the UK were often influenced by their paid-carers (Bannerman *et al.* 1990; Keywood *et al.* 1999; Rodgers 1999).

An Australian study identified barriers to breast screening of women with cerebral palsy (who often have associated problems related to LD) using focus groups with radiographers (Poulos *et al.* 2006). The barriers which were identified included lack of accessible information, poor access to the mammography machinery and problems with positioning. They also noted communication as a major concern during the procedure and the time constraints for attending to the individual needs of the women. Furthermore, the opinions, beliefs and attitudes of radiographers were also seen to impact but were more difficult to modify. As few details were documented about the representativeness of the sample, such as the numbers used, further evaluation of this study was difficult.

Undertaking this review, it was noted that nurses' views on barriers to screening may have also been found in studies looking at general health checks such as that reported in Hunt, Wakefield and Hunt (2001). As such research was not specifically related to breast screening, a decision was taken not to pursue this part of the literature.

2.3.4. Other barriers to attending breast screening

Much of what is outlined in this chapter is taken from articles already reviewed elsewhere. Other material used to demonstrate these issues is not critically examined unless it related to women with LD and breast screening. Much of

the literature referred to in this section was reviewed to highlight other issues that might prevent or potentially deter women with LD from attending breast screening. One gap in the literature that was identified was the lack of views from family-carers about breast screening in women with LD. Outside the screening literature (which will not be reviewed in detailed), it has been noted that paid and family-carers have experienced difficulties in identifying ill health in those they care for, and this can be compounded by a reluctance to seek help (Alborz *et al.* 2003; Beange, McElduff and Baker 1995; Kerr *et al.* 2003). Identification of health issues was most problematic in people with profound LD (Rudkin, Heason and Rowe 1999; Thornton 1999). Identification of health problems can be aided by long-term relationships between people with LD and their paid-carers or family members (Donovan 2002; Singh 1997). Conditions that cause gradual deterioration were found to be harder to identify and their diagnosis and treatment often depended on the assertiveness of the carer (Alborz *et al.* 2003; Kerr *et al.* 2003).

Barriers identified anecdotally within both the UK and international literature (which have been referred to earlier) include: the individual's physical and intellectual ability level; the ill health of either women with LD or their carer; moving into a nursing home or into another area; issues such as transport; consent; and fear of the procedure and embarrassment (Davies and Duff 2001; Isaacs 2006; Sullivan *et al.* 2003; Sullivan, Slack-Smith and Hussain 2004). Many of these barriers were consistent with those found in the general population. These studies are not reviewed but are mentioned for comparison purpose only (Guilcher, Newman and Jaglal 2010; Nosek and Howland 1997; Wee *et al.* 2000).

The experiences of women with LD going for breast screening were also comparable to the experiences of women in the general population going for cervical screening: anxiety, embarrassment, lack of appropriate information and difficulties over giving consent. Physical disability and poor literacy were also identified (Djuretic *et al.* 1999; Pearson *et al.* 1998; Reynolds, Stanistreet and Elton 2008; Wood and Douglas 2007). This again is consistent with work on the general population (Bruyninckx *et al.* 1999; Hamilton and Barlow 2003; Keefe *et al.* 1994; Sutton *et al.* 1994). As with the breast screening literature, barriers to

cervical screening revealed poor attitudes held by screening staff and GPs towards women with LD. British work has shown that GPs do not to recommend routine cervical screening for women with LD because they consider it to be unnecessary (often because they think the woman are asexual) or because of consent issues (Djuretic *et al.* 1999; Pearson *et al.* 1998; Stein 2000). Although there have been reported difficulties in gaining consent from either the woman or their carer, difficulties in obtaining consent should not prevent women with LD from going for screening (Djuretic *et al.* 1999; Haire, Bambrick and Jones 1992).

Of the many barriers identified, the centralised invitation process (where women with LD are invited to screening by letter) was thought to be a significant factor in accounting for low participation in breast screening. Most countries use a centralised process and identify women eligible to attend for screening using a list. France, for example, uses listings from the *Sécurité Sociale* whereas Australia uses the voting register because voting is mandatory for Australians (although people with LD are exempt from voting). In the UK, women are only offered breast screening if they are registered with a GP. Some people with LD do not know how to register with a GP, and a GP can refuse to take the person onto their books. Many people with LD are not registered with a GP (Biswas *et al.* 2005) hence access to the same services as the general population through social inclusion has not taken place. Although women can self-refer to the Breast Screening Unit, the challenges of how women with LD actually did this were highlighted anecdotally by Sullivan *et al.* (2003) and Sullivan, Slack-Smith and Hussain (2004). One criticism of using a centralised system is that it treats the population as homogeneous and disregards women who are atypical and unrepresentative of the general population, as McKie (1995) noted when talking about cervical screening:

> *'Health care professionals assume that all women are heterosexual without any experience of sexual abuse or trauma concerning such conventions and internal examinations'* (McKie, 1995: 453).

The centralised system was found to make no allowances for those with literacy problems, so women (including women with LD) who were unable to read or understand the invitation would inadvertently be missed (Isaacs 2006; Pearson

et al. 1998). In Britain, although adapted letters tailored to women with LD are available, not all Breast Screening Units were aware of women with a LD and consequently no extra time, adapted information or an appropriate invitation were allowed for (NHS Cancer Screening Programme 2006). British work on cervical screening with 62 women with LD indicated a reluctance to use amended letters by some GP practices (Pearson *et al.* 1998). Financial considerations about developing and sending out these letters also had to be accounted for. In countries where screening is not free, such as the United States, this was seen to contribute to lower up-take (Kelaher and Stellman 2000). Even where screening is free, as in Britain, hidden costs were still identified, such as staff or the woman's time and transport costs (Isaacs 2006). Transport costs were also acknowledged in the international studies (Sullivan *et al.* 2003 [Australia]; Proulx *et al.* 2008 [Canada]).

In summary, similar barriers to breast and cervical screening for women in the general population and those experienced by women with LD were highlighted. Although some studies had accessed data directly from women with LD, few were published so comparison and evaluation was difficult. A number of studies identified primary care providers as inadvertent barriers whilst other studies have identified poor knowledge and limited understanding about the needs of people with LD. The same could be said for those who are also cognitively compromised. Paid-carers were able to identify the barriers to access and were also seen as pivotal to supporting the women. An understanding of the dynamics of all those involved in preparing and supporting a woman through breast screening has not yet been pursued. Family-carers have not been consulted about their role in supporting women through breast screening and there is limited evidence from professionals such as nurses and radiographers. Work in the UK is specifically needed, as the makeup of the service is dependent on both health and social care workers. An understanding of the dynamics of their interactions would help to fully explore potential barriers.

2.4. Appropriateness of breast screening

The question about whether breast screening was appropriate in women with severe or profound LD, mental, or physical disabilities and women with DS was also raised within the discussion of the literature by the following researchers (Satgé and Sasco 2002; Sullivan and Hussain 2004, Wilkinson and Cerreto 2008). Evidence from France has suggested not repeatedly screening women with DS due to the reported lower incidences of breast cancer (see section 3.3.3). Furthermore, women with DS are thought to be more vulnerable to ionising radiations, particularly X-rays (Satgé and Sasco 2002). This suggests the need to consider alternative means of breast surveillance. Wilkinson (2008), in her commentary paper, highlighted the controversy regarding this, and reported that the current consensus suggests following the guidelines for the general population (Wilkinson, Culpepper and Cerreto 2007). Similar controversy over alternative methods can be found in the review paper on the cervical screening literature for women with LD (Sullivan, Satgé and Willis 2010). A similar literature has been raised over cognitively compromised older women in the general population in the United States (Wolfson *et al.* 2001).

Breast surveillance is not as efficient in detecting breast cancer as mammography (NHS Cancer Screening Programme 2006). However, women with LD (in common with any women in the general population) who are unable or unwilling to attend for breast screening should be encouraged to be 'breast aware'. Not all women with LD will have access to breast awareness initiatives, due to them (or their carers) not being aware of such initiatives, or it being regarded as inappropriate for them. A number of breast awareness initiatives were identified in the literature search, but most of these papers merely described what the initiative was about and did not detail numbers of participants. Some provided education about breast health and breast screening for women with LD, others for paid-carers as well (Cowie and Fletcher 1998; Gaze 1998; Poynor 2003; Symonds and Howsam 2004). Check lists were often favoured and included looking at the appearance of the breast, checking for lumps or changes, noting any discomfort or pain and observing the nipple for any discharges or rashes. Given the limited information on outcomes and the localised use of these initiatives, an individual evaluation of these

studies was not undertaken. However, the issues raised about breast awareness in the papers are discussed below.

Many women with LD do not have the motor or cognitive skills to perform or understand breast checks and are reliant on their carer to look for relevant breast changes (Hogg and Tuffrey-Wijne 2008). Issues raised within the literature (already reviewed above) on this topic have included carers feeling unable or untrained to provide support or education, while others consider health support to be the remit of the health professionals (Davies and Duff 2001; Poynor 2003; Royal College of Nursing 1999; Smyth and Bell 2006; Sullivan, Slack-Smith and Hussain 2004). Studies looking at training staff in this area have reported different views. Coultas and Capper (1996) reported on a breast awareness project that aimed to increase awareness of breast self-examination through a teaching intervention given to women with LD by LD nurses. Although awareness of breast examination was reported as increasing, the merits of this study are difficult to determine because few details were given about the numbers participating or how awareness was measured. Cowie and Fletcher (1998) reported on a pilot scheme whereby breast examinations were conducted on a monthly basis by the service users (women with LD) or suitably trained staff on their behalf. Training was provided for qualified nursing staff within the Trust and covered issues such as breast cancer prevention and breast awareness. No details were given about the numbers who participated. During the evaluation, the protocol was changed to include identifying changes in the breast during normal care routines, such as bathing and dressing, as opposed to formal, clinical examination. Again, the merits of this study cannot be thoroughly evaluated because no details were given about the number of people involved or the evaluation process.

Similar interventions were introduced by Poynor (2003). She developed a training pack with multidisciplinary team members for women with LD and their paid-carers. The pack was evaluated individually by 10 women with LD and by three women's group who had support from health professionals and paid-carers. Although the pack was evaluated, the evaluation only took the form of comments from the women and the people who supported them and the number of participants involved in the feedback was not documented. Poynor

(2003) stated that there was unanimous agreement on the usefulness of such a pack in promoting breast awareness from those in the pilot study. Additionally, views were sought from 50 different professionals (the disciplines of these professionals were not documented), with 30 responding (60%) and these were all supportive of the package. Gillings-Taylor (2004) in her review paper highlighted that training paid-carers to undertake breast checks may not be cost effective, as the benefits would not outweigh the expense, given the numbers of paid-carers that would need to be trained. Symonds and Howsam (2004) devised a checklist to enable accurate recording of monthly observations and a resource pack which featured pictures of breast conditions, guidelines for completing the checklist and local resources. This was seen to improve breast awareness in the women with LD and paid-carers but few other details were documented including the number of participants. Gaze (1998) reported on an initiative that aimed to train paid-carers to undertake breast examinations of the women with LD whom they supported. Although no details were provided on the number of paid-carers and women involved, Gaze highlighted the ethical committee's reservations about carers undertaking breast checks. The ethics committee recommended that breast checks should be performed by a nurse who did not know the woman and in a clinic away from the home.

Carers who refused to perform breast checks could also be seen to be failing in the duty of care (Gillings-Taylor 2004). However, a statement by the Royal College of Nursing (1999) suggested that only trained specialists should perform breast checks and highlighted the limited guidance for carers about breast screening. Only one example of good practice guidelines was found which was issued by the NHS for breast and cervical screening in women with LD (NHS Cancer Screening Programme 2006). This was a guide to undertaking breast and cervical screening for health professionals.

Coultas and Capper (1996) noted the general paucity of breast care knowledge in nurses working within health care settings, and the need to raise awareness around the needs of people with LD among Primary healthcare staff. No details were given about the study such as the number participating, which again limited the evaluation that could be made. Similar issues about knowledge were raised with clinical staff undertaking cervical screening (Shaughnessy 1999).

This suggests an important role for community LD nurses is potentially being missed (Broughton and Thomson 2000). Whereas Taggart, Truesdale-Kennedy and McIlfatrick (2011) noted that when discussing with CLDNs about teaching family-carers to examine the breasts of the women with LD they support if they were unable to self-examine, concerns were raised relating to 'vulnerability' and the potential issue of 'abuse' that this may create.

The parallels within the cervical screening literature on up-take and that on breast screening up-take are striking. Preparation for cervical examination was seen as essential. Shaughnessy (1999) initiated training for the staff who cared for women with LD to help them support the women through the screening process. The numbers trained were not disclosed. Of the 126 eligible women with LD identified in the study, 40 did not take part due to either moving out of the area or refusing to participate. Of the 86 attending their appointments, 25 were deemed ineligible due to immature genitalia or their hymen still intact (which would make the procedure painful), whilst 18 withdrew consent. In total 45 women with LD underwent a cervical smear. Although some women were unable to have the procedure performed, having the staff who supported them present when undergoing their cervical smear was deemed important, especially with obtaining informed consent and explaining the procedure to the women.

Broughton and Thompson (2000) interviewed 52 women with LD and 34 paid-carers about cervical screening. They report that 75% (39) of women were unsure of the purpose of the test. They also reported how preparation for the procedure was important in reducing anxiety and fear in the women. Having a female clinician perform the procedure also reduced embarrassment (Broughton and Thomson 2000). GP practices offering preparatory consultations and/or long appointments for women with LD tended to be on an ad hoc basis (Wood and Douglas 2007). Furthermore, the lack of interest reported by GPs in learning more about how to deal with patients with LD suggests that without enforcement, guidelines, such as the one issued by the NHS Cancer Screening Programme (2006), are unlikely to be put into practice on a wide scale (Pearson et al. 1998).

In summary, for some women with LD, breast screening remains a difficult procedure to undertake, while for those with DS it may arguably do more harm than good. Despite this, breast surveillance has been included as part of these women's health routines. A number of difficulties with undertaking self-examination surveillance were noted and the lack of guidance for carers assisting with this was also identified. It is therefore important that carers' views and the remit of their role and that of others be considered in future work as they may be pivotal in helping the women access breast screening and maintaining surveillance of the breast outwith the screening process.

2.5. Improving breast screening up-take?

Improving up-take of breast screening in women with LD has tended to focus on educational initiatives. A number of British studies have tried to improve up-take, but limited reporting makes evaluation of these studies difficult. Pehl and Hunt (2004) examined informed choice for women with LD when undergoing breast screening. They developed a joint working protocol involving both health and social care sectors. This ensured that both services were aware that breast screening was taking place and that all women with LD were identified to the Breast Screening Unit. However, the number of participants involved in the study was not stated. The work was presented as a protocol, which commenced when the Breast Screening Unit informed the liaison nurse (a nurse who acted as an intermediary between the patient, carers, and the particular service) that screening was being introduced in a specific area. The liaison nurse would then contact the local LD nursing team to ascertain if there were specific difficulties and would offer 'practical assistance' at this stage (the assistance offered was not defined). If a woman failed to attend the breast screening session, the liaison nurse would be alerted and the 'intervention' (a visit to the woman devised to supply information and training) would be offered. A criticism of this study is that it suggests that women who attended breast screening had made an informed choice and women who failed to attend had not.

Davies and Duff (2001) have previously suggested through their work that some women simply attend without really understanding the procedure. Evidence

about the nature of non-attendees at screening is often based on anecdotal evidence and the assumptions held by healthcare staff, which is seen to reinforce the divisions between experts and lay people around the most intimate dimensions of this bodily experience (Gregory and McKie 1993; McKie 1995). Perhaps a better route would have been to offer all women with LD some education or training, although this again would be problematic for women with severe LD.

As with studies in the general population, work with women with LD has looked at the impact of education and training on up-take. One British initiative identified eligible women with LD through nursing and social services registers along with their carers (Isaacs 2006). The number of participants involved in this study was not discussed. The women were given training and education three months prior to attending breast screening. To help improve access and knowledge, women identified as having LD were also sent adapted letters inviting them to attend breast screening. Up-take was reported to have increased, but little is known about whether the women's knowledge increased, as only average up-take was reported over a 14-year period since the system was first introduced. Although Isaacs (2006) does not discuss choice in presenting for screening, an editorial reported the study in terms of all those wanting or able to participate rather than a suggested mandatory participation (Duffin 2009). Duffin (2009) also reported the percentage up-take had increased from 41% to 73%, but once more, any gains in the knowledge of women with LD were not reported. Davis (2008) in another editorial reported an increase in the percentage up-take from 31% to 100% in breast screening in women with LD with a similar intervention in Walsall in the UK (no further details were given). Neither Duffin (2009) nor Davis (2008) detailed the number of women involved.

Increased knowledge of breast awareness and up-take of breast screening for women with LD living in residential care was investigated by another UK study (Symonds and Howsam 2004). Here LD teams developed a teaching pack, check list and resource pack covering breast awareness and preparing clients for breast screening, for staff working with women with LD. The training was aimed at carers and was undertaken in residential homes by a breast care and

community LD nurse. The number of women and carers involved in the study was not reported. Staff were discouraged from undertaking physical examinations but were advised to use the checklist to document any observed changes in the client's breast found whilst carrying out personal care on them. Evaluation of the scheme found that 50 homes were involved and suggested that the scheme had been well received. No subsequent publications could be found so comment cannot be made about whether up-take has improved or referrals for breast screening have increased.

Ramessur-Marsden *et al.* (2008) also devised a health education package to support women with LD through cervical and breast screening. Working with teams across North and North-East Wales, they devised a training pack which consisted of a tool kit (cervical screening only), a care pathway and a checklist. The packs could be used by a group or in one-to-one situations and commenced from invitation to screening to results of the test. A representative from each community LD team across North Wales was invited to attend a training event by the screening service to launch the packs (the number of representatives attending was not documented). The packs were then piloted across North Wales for six months. To evaluate the pack, follow-up questionnaires were devised for both women with LD and the health care professionals who were using them. These requested participants to rate the pack on a scale of 1 (poor) to 5 (excellent). Interviews were also conducted on those (presumably health professionals, although this was not stated in the paper) who had agreed to participate in the pilot study. Results were poorly detailed and exact numbers of participants were not stated although their responses were represented by a graph indicating the relevance, ease of use, format and information in the pack. From this graph, only seven participants were seen to have replied but this may not represent the actual number of participants involved. Little further details were given, other than making a number of recommendations. The study was well planned, but the results give little indication of how effective the resource was and whether knowledge and understanding had improved. Decision making was seen as integral to the resource but again few details were given about this.

In trying to increase the up-take of breast screening a number of resources have been produced. Many of these have been disseminated through editorial or freelance articles in the popular nursing press such as the *Nursing Times*, hence full evaluations of these products and interventions has not been undertaken. Many of the resources have been produced with the intention of providing accessible information using DVD and information in booklets for women with LD. An initiative in Leeds which utilised a resource pack for women with LD was reported by Davis (2008), but few details were given about the success of this resource pack or the number of participants involved. In a similar report, Duffin (2009) reports on a snakes and ladders game devised by Greater Manchester Primary Health Care Trust, aimed at teaching women about breast care and screening. Again the number of participants was not detailed. Breast Test Wales have also devised a training pack (NHS Wales 2008). These resources complement more established publications from Family Advice and Information Resource [FAIR] (2005), Hollins and Perez (2000), NHSBCSP (2006), all of which are booklets specifically depicting a woman with LD going for breast screening. As little or no evaluation of the effectiveness of these initiatives and resources has been undertaken, they have been merely noted rather than reviewed in detail.

Although it was not the intention of this literature review to compare the literature on women with LD against that on women in the general population regarding increasing breast screening up-take, it was interesting to note that there was an absence of using the media, such as television, books, papers or films. Television coverage portraying Sally Webster's breast cancer in Coronation Street and the death of the reality TV personality Jade Goodie were both found to have substantially increased the up-take in breast and cervical screening (NHS Cervical Screening Programme 2009; Bowring and Walker 2010). There was no literature about using the media to increase awareness for women with LD. The reason for this may have resided in the fact that media campaigns have been found to be too abstract for women with LD to understand the key messages (McCarthy 1999).

Within the educational projects there was an emphasis on the women being screened rather than encouraging them to make an informed choice. This was

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seen to be no different to the emphasis in material aimed at the general population. The discussion in the British literature on how to increase up-take is dominated by two concepts: making breast screening mandatory or administering breast screening in the same way as cervical screening with incentives for GPs (Marks *et al.* 2005; Marteau 1993; Ogden 2007). Making breast screening mandatory has been viewed as untenable. Unlike mandatory immunisation, which could be supported on the grounds of risk to society and public health, a similar policy on breast screening for reasons of preventative health could not be justified (Singer 1993). Mandatory screening would take away the right to choose and would be an infringement of personal liberty and control over women's bodies. The second proposal for monetary incentives for GPs to ensure that a certain percentage of women are screened is similarly problematic. Funding bodies are seen to be interested only in achieving the targets set and are not interested in reasons for non-compliance at screening. McKie (1995) has suggested that this explains why some women's experience of screening is poor.

In summary, many of the interventions aimed at women with LD mentioned in this section to increase up-take have focused on British work. As with initiatives directed at the general population, these have produced pockets of good practice and some useful materials. Much of the work is localised and neither the initiatives nor resources have been nationally evaluated. Outcomes are poorly reported in the literature and do not specify previous preparatory work. There is a strong emphasis in these initiatives for the women to be screened rather than encouraging them to make an informed choice about the process. The literature review identified a need for a full, critical review of interventions and resources before further investment and work is undertaken. Once this has been conducted future considerations about interventions and resources could be explored in order to help women with LD make an informed choice about whether they access screening.

2.6.   Summary

British and international studies on cancer in people with LD highlighted a different profile from that apparent in the general population. More specific

studies on breast cancer in the LD population were limited and often focused on women with DS because of the protective properties the syndrome is thought to bestow. Thus evidence from more general studies on cancer was considered within the evidence of this review. This complicated the picture as there were few details about the populations studied or the methods employed to collect data, which meant that meaningful comparisons were sometimes difficult to make. The general consensus was that the incidence of breast cancer was the same if not lower in women with LD, especially among women with DS.

Generally, more studies specifically concentrating on breast cancer are needed in this area. Despite breast cancer having an inherited component there is a scarcity of research looking at inherited breast cancer in women with LD. Although a number of small scale British projects have been undertaken, more population and data linkage studies are needed and this would enable better comparisons. The review also highlighted difficulties for future work insofar as it suggested cancer profiles differed depending on the severity and aetiology of LD. Future research should concentrate on establishing whether there are any implications for women with DS attending breast screening and to explore the risk of breast cancer in people with severe LD.

The reported low up-take of screening services has been consistently suggested as a reason why breast cancer incidence may be lower in women with LD, as lower attendance would mean fewer breast cancers being detected. Despite this, the review found that low up-take of breast cancer screening in women with LD was seen as the norm and little work had been undertaken on the health beliefs of women with LD. Although a number of barriers to screening up-take were identified, these were mainly based on small scale-surveys with only one population-based data-linkage study. Several researchers noted higher up-take but again their projects were small-scale and had methodological flaws making findings difficult to compare. At present, the factors preventing the women from participating is really unknown and more work is needed in this area.

Although findings about barriers to participation are on the whole similar to those faced by the general population, few studies have investigated the views

of women with LD. Furthermore, how the women came to go to breast screening or the influences, preparation and decisions prior to attending also remain unknown. Limited understanding about the role of GP, mammographer and paid-carers were observed. Poor knowledge about the health needs and communicating with people with LD was also noted among professionals not specifically working within the field of LD. While paid-carers were identified as being pivotal to supporting the women, there is little support for them. Surprisingly little work has been undertaken on the role of the nurse in supporting women with LD through breast screening. Little guidance for carers or practitioners who support the women, especially in surveillance and breast awareness outside of breast screening, was found. Given the diversity of people and services, women with LD potentially come into contact with, understanding the dynamics of these interactions and their impact on the decision to participate in breast screening need to be explored. Undertaking more work on in this area would further clarify the potential barriers, especially if the work was undertaken from the women's point of view.

A number of interventions to increase up-take have been initiated, although generally they have been poorly reported. Conclusions about whether up-take was increasing were hard to establish. Reports on such interventions have mainly referred to Britain. The work has produced pockets of good practice and potentially useful materials, but there has been no national co-ordination of these initiatives (despite breast screening itself being a nationally co-ordinated service). One failing of these initiatives is the assumption that women who do not attend do so due to a lack of education rather than by their own choice. Insistence on being screened also fails to take account of work undertaken on women with DS who may be potentially harmed by the procedure and the difficulties for women with severe or profound LD. A review of interventions and resources is needed, before further investment and work is undertaken.

One significant gap identified in the literature is that no studies have examined breast screening in women with LD in Scotland. This is imperative as health is a devolved power held by the Scottish Government and the Scottish health service differs from elsewhere in the UK. Little work has explored or examined where women with LD (and those who support them) obtain their health

information. Little to no guidance exists for either the women or their supporters in this area. This is seen as a crucially important concern. There is also a lack of knowledge about the preparatory work necessary and how other support and health staff work together to help the women decide whether to participate in the programme. After all, if a woman does not understand breast screening, or has not had it fully explained to her, it is questionable whether she should be participating in the programme in the first place.

Chapter 3:   Methodological issues

3.1.   Introduction

This chapter is divided into five parts. In part one, the rationale for the research approach adopted and the underlying theory related to the research design are discussed. In part two, the justification for the data collection techniques employed – observation, interview and field-notes – are presented, before proceeding to detail how they were used in the study. Part three discusses ethical approval and the issues of consent that arose from this. Part four explains how the participants were selected and recruited. Data collected for this study concerned the views and experiences of 12 women with LD about breast screening. As these women need support with daily life and accessing health services, the views of 10 paid-carers, 3 family-carers and 10 allied-professionals were also considered. Part five examines how the data was analysed, the choice of framework and the decisions made to arrive at the final themes. In conclusion the means of ensuring the trustworthiness of the data are outlined.

The chapter was structured in this manner in order to provide a clear account of all the stages involved in the study. Throughout this chapter, I have first presented the theory before explaining the rationale for the choice of approach or methods, how this was executed within the study and then offered a reflection on this. The first person is used to acknowledge and identify the areas in which I was part of the research process and that I had personal involvement with the research (Horsburgh 2003).

The literature review identified gaps within current knowledge which enabled me to formulate the overall aim and research questions that drove the research.

3.1.1.   Overall Aim

The overall aim was to explore the influences on and experiences of women with LD who were invited to participate in breast screening. From this, two research questions were developed:

3.1.2.   Research questions:

- How do women with LD experience breast screening?

- What are the factors that influence women with LD to participate in breast screening?

3.2.   Part one: Design

When conducting research the researcher must make a number of decisions. In this section the ontological and epistemological positions will be stated. The rationale for adopting a qualitative approach will be discussed as will the choice of participatory research. The design employed in the study will then be examined and a detailed justification offered for the choice of focused ethnography.

3.2.1.   Perspectives

The researcher must consider the perspective they will take towards their proposed research and this is often termed their 'research paradigm'. The research paradigm can be defined as their understanding of reality and the nature of knowledge in their chosen field of enquiry (Barbour 2008; Denzin and Lincoln 2005). Put more simply, it is a basic set of beliefs or assumptions that that guide the enquiries (Cresswell 2009). Mason (2002) has suggested that this relates to three principles: ontology (what constitutes the social world and how it is studied); epistemology (theories of knowledge and the nature of evidence); and method (how to gain knowledge of the world).

In creating a research paradigm, the researcher must define their ontological position or perspective (Barbour 2008). The aim of my research was to explore the influences on and experiences of breast screening in women with LD. My principle intention was to understand what breast screening was like and what influenced participation from the women's perspective. This also reflected the principles of participatory research, in which people with LD participate in the research; in doing so their views are heard and conveyed through the findings of the research (Booth 1996; Burke *et al.* 2003; Knox, Mok and

Paramenter 2000; Walmsley and Johnson 2003). To find out what constituted the women's social world I believed that the best approach was to observe their world and ask the women and those who supported them about this experience. Only by understanding the participant's ontological position on breast screening and what influenced this, would I be able to understand what the reality of having a mammogram was like from their perspective.

Mason (2006:16) stated that 'epistemology concerns the researcher's theory of knowledge, how they come to know the world and how the knowledge can be demonstrated. Hence this concerns the principles and rules by which the researcher decides whether the social phenomena can be known'. Deductive methods such as testing a hypothesis are seen as one way of generating knowledge which can be used to form a theory about a phenomenon. Development of a theory was not the intention of my research, but as Mason (2002) suggested, it helps to demonstrate the relationship between epistemology and method. My literature review facilitated the exploration of the nature of knowledge and helped to shape the design of the study. An example from the literature were those studies that had used interventions such as education programmes to help the women attend breast screening. Although these studies demonstrated a higher up-take, they did not tap into what the experience of breast screening was like for a woman with LD. The literature review enabled consideration of a number of methods. It also drew attention to the need for the views of the women with LD, those who would be involved in supporting them through and performing breast screening on them (namely carers and allied-professionals) to be heard and their experiences captured at first hand. For these reasons observation and interviews were selected as the primary data collection methods.

When discussing the nature of knowledge, two paradigms, positivism and naturalism require addressing (Guba and Lincoln 1994; Morse and Field 1996). Quantitative research has been influenced by positivism and is characterised as being closer to the natural sciences' method of scientific enquiry because numerical data are obtained (Bryman 2008). This is often considered to put 'distance' between the participants and research, both socially and psychologically. Qualitative research, through the influence of naturalism, has

embodied the proposition that social reality is constantly changing and cannot be understood by precise measurements (Bryman 2004). Rather than the experimental method and measurements, the voices of the researcher and those being studied become crucial to understanding the phenomenon and are the product of the interaction between researchers and participants (Barbour 2008). This approach minimises the distance between the researcher and those being researched. To characterise the difference between the two paradigms, a quantitative researcher may seek evidence of how much of a particular type of experience has been gained whereas the qualitative researcher may ask what the experience was like.

Despite differences between the paradigms, both approaches become reductionist towards their data sets in order to make sense of them (Hammersley, Foster and Gomm 2000; Trochim 2000). Rather than postulating a distinct dichotomy, Trochim (2000) has suggested that the qualitative versus quantitative debate is 'much ado about nothing' as there is value in combining both methods. However, a distinction must be made between the philosophical underpinnings of quantitative and qualitative approaches and the corresponding data collection techniques. Whereas the data collection methods can be combined, their epistemological positions cannot (Richardson 1996).

3.2.2. Justification for using a qualitative approach

A number of studies in the literature review employed a quantitative approach. To understand the incidence of breast cancer in women with LD, population data was analysed. However, this type of study could not answer the questions about the women's experience or influences. The HBM (Ogden 2007) and TRA (Ajzen and Fishbein 2004) used questionnaires to predict breast screening up-take. Although the models were potentially useful in that they could be used to develop predictors of up-take of breast screening, no studies were found that included women with LD. This in itself could have been considered a reason to undertake such a study, but the methods used to ascertain this type of information were not wholly suitable for women with LD due to literacy problems.

Other studies of up-take of breast screening used surveys or questionnaires (Davies and Duff 2001; Piachaud, Rohde and Pasupathy 1998) but again the experience of breast screening and the influences that the women were exposed to were not captured. In addition, a quantitative approach reflected the trend to test and measure people with LD rather than exploring their experiences or improving their status (Northway 2001). Consequently, quantitative research was seen as antipathetic to the philosophy of inclusive research. The empirical basis of this study was to understand the experience of breast screening from the women's perspective. This again justified rejecting a quantitative approach. Within the literature only two studies had previously asked the women about breast screening directly. Proulx *et al.* (2008) used interviews and asked about the barriers; Truesdale-Kennedy, Taggart and McIlfatrick (2011) employed focus groups to explore a number of topics including their experience of breast screening. This indicated a deficit in knowledge about the women's experience and offered support for adopting a qualitative approach. Such an approach complemented the premise of the research as well as the idea of inclusive research in that the views of women with LD would be heard and their experiences acknowledged.

Experiences come from knowledge and participation in activities. Qualitative research accepts that knowledge is socially constructed and that experiences are subjective and cannot be quantified but can be described (Mason 2002). Qualitative research permits the use of approaches that enable the participants to be studied in their natural settings with the researcher being situated within the culture, thus allowing reality to be reflected in terms of what is said and experienced (Barbour 2008). This enables the complexities of these factors to be captured since being situated within a specific social world permits actions and views to be explored simultaneously rather than studying them as isolated elements. For my study, a qualitative approach using observation and interviews was necessary to uncover the shared experience of and influences on women with LD when they attended for breast screening. It would enable me to talk to participants and observe them in the period leading up to and during breast screening.

3.2.3. The influence of inclusive research

Inclusive research must also be mentioned because this also influenced the approach selected. The researcher needs to choose between emancipatory and participatory research. Participatory research was chosen for this study because it allowed women with LD to be involved in the research but left ultimate control of the work undertaken with the researcher (Chappell 2000; Walmsley 2001). Having the researcher retain control was important because this was a doctoral piece of work which necessitated the researcher (myself) to demonstrate ultimate responsibility for a substantial project. The study utilises the principle of participatory research because the topic under study was identified in previous work I had undertaken with women with LD and their paid-carers (Willis, Wishart and Muir 2010; 2011). This study also enabled the women with LD to give feedback on the development of the data collection methods and findings. It meant that the views of women with LD about their experience of breast screening and the factors that influenced them to participate are captured and conveyed through the findings of this research which may go towards improving their experience (Booth 1996; Burke *et al.* 2003; Knox, Mok and Paramenter 2000; Walmsley and Johnson 2003).

3.2.4. Choosing the research design

It is important that an appropriate research design was employed (Pope and Mays 2006). The aim of this study was not achievable using a quantitative approach. However, within qualitative research there are number of potential designs. Boyle (1994) suggests that researchers must decide which design best suits the work they intend to undertake. Phenomenology was rejected because I was not predominantly looking at the meaning of the experience of breast screening (Smith 1996). Similarly, Action Research was rejected because little was known about the issue of influence and experience of breast screening from the women's perspective. Until more was known, progressive problem solving would be inappropriate. Grounded Theory was unsuitable because the way the women interacted with the world was not understood; in order to develop a theory it would be necessary to comprehend how the women experienced their world. In order to grasp this and capture what occurred prior

to and during breast screening I drew on an ethnographic approach. This was because I believed that this design enabled the women's actual experiences to be recorded and the complex influences which affected their participation in breast screening to be revealed.

3.2.5. Ethnography

Ethnography was associated with the anthropological tradition (the study of humankind) which endeavoured to interpret and understand a culture (or way of life) from an outsider's point of view (Morse and Field 2002; Silverman 2000). It evolved from a form of anthropology, ethnology, which drew on individual accounts of human cultures encountered by travellers and missionaries outside of the Western world (Hammersley and Atkinson 2007). Ethnology fell out of favour as anthropologists drew on their own fieldwork, rich descriptions and theories of the culture in which they had been immersed. From this development, ethnography emerged and ethnographers began to present holistic accounts of particular groups of people: for example, Malinowski (1922) analysed the Trobriand Islanders, Mead (1928) documented adolescence in Samoan girls, whilst Evans-Pritchard (1940) wrote about the Nuer. In these ethnographies, definitive information about these various groups was provided; for example, the reader of Evans-Pritchard's ethnography learns that the Nuer had a segmentary lineage organisation. Segmentary lineage organisation had two functions: first, even very distant kin would automatically put their conflicts aside and unite against any threat from non-kin groups; and second, it played a significant role in regulating inheritance and property rights. What emerged from this corpus of work was that there were common understandings and practices within all cultures. To capture rich data about specific cultures, traditional ethnography required the ethnographer to spend long periods of time in a particular place, learn the local language and to become part of the group being studied.

Years after Mead completed her work, Freeman (1983) spoke to some of her original informants and drew very different conclusions about adolescent girls in Samoa from Mead. The critique suggested that Mead was misled by her informants and Freeman's work raised questions about how informants'

perspectives and understandings could change over time. It also raised concerns about how interactions with different researchers could influence the information gleaned through ethnography. Although Mead's work remains a significant pioneering contribution, it raised the importance of critical evaluation of the data sources, collection methods and the role of the ethnographer. Similarly, several decades after Malinowski's work in the Trobriand Islands, Weiner (1976) undertook a follow-up study. She highlighted the role of women in everyday economic activities which suggested that Malinowski's account of the kula ring as an elaborate system of symbolic exchange provides only a partial understanding of economics and exchange in the Trobriand Islands. Weiner identified that Malinowski had not paid proper attention to the important activities of women, and that he had failed to take full account of gender and women's roles. Through the critiques of Weiner and Freeman, ethnographers now place methodological emphasis on multiple perspectives and subjective positions within their work.

Although ethnography originally focused on foreign cultures, it has broadened into the observation of everyday life. Delamont (2004) suggested this was due to the influence of sociology and the rise of the 'Chicago School's' influence on urban social phenomena, where marginal members such as street gangs, slum dwellers and the family were examined in Western culture. Examples include Whyte's (1955) *Street Corner Society,* a study of an Italian slum in Boston; Thompson's (1967) record of joining the Hell's Angels; and Patrick (1973) *A Glasgow Gang Observed*, an account of a gang in the Maryhill area of Glasgow. Since then, researchers in other disciplines, such as education and nursing, have employed ethnography to analyse their own culture (Morse 1994; Morse and Richards 2002). Oakley (1974a and b), for example, studied *The Housewife* and *The Sociology of Housework*, later looking at the medical care of pregnant women (Oakley 1984). These were the first sociological studies to treat domestic work as 'labour' rather than simply an aspect of the feminine role and to relate the medicalisation of pregnancy to patriarchal attitudes in women's healthcare (Oakley 1974a and b; 1984).

Like all qualitative approaches, ethnography is inductive, proceeding from the specific to the general hence no hypothesis guides the researcher toward the

outcome of the inquiry. Ethnography differs from other qualitative designs in that it focuses mainly on routine activity, customs and cultures (Gerrish and Lacey 2006). Descriptions, observation and interviews are the main research tools used, although documents, chance encounters, overheard conversations and notice boards can all form part of data collection (Parahoo 2006). Atkinson *et al.* (2001) have argued that the researcher is the main research tool because of their first-hand experiences about the group or community being studied. Ethnography has been typically described as understanding a culture by learning from the people within it (Roper and Shapira 2000). The central characteristic of ethnographic work is immersion in the setting, although the emic and etic perspectives and thick description are equally important (Gerrish and Lacey 2006). It is these concepts that have defined ethnography and these are discussed below.

Immersion into the culture under study enables the researcher to learn from the people within it. Culture can be defined as the way of life of a group, the patterns of behaviours that are socially constructed and transmitted, how individuals share the culture and values and how they are acquired (Silverman 2000). In nursing, Hammersley and Atkinson (1995) have suggested that in addition to understanding the culture, improving professional practice is a central feature. When immersed in the culture, the researcher learns about the values and becomes socialised into the culture and the behaviour within it (Morse and Field 2002). Interpretation of the social world is considered important and is often based on tacit knowledge (Mason 2002). Tacit knowledge is defined as the knowledge that the members of the culture share but do not articulate to each other: this is what the researcher must uncover and make explicit within their findings (Mason 2002). In relation to this study, in order to understand the factors that influenced the women and their experience of breast screening, the researcher would need to be immersed in the women's culture in order to understand the routines and rituals within this environment. A criticism of ethnography is that while the researcher's aim is to understand the way in which people live, this is often explained from his/her own point of view (Spradley 1980).

The terms 'etic' and 'emic' are frequently employed in ethnographic research. The etic refers to the researcher entering the field with an 'outsider's view' and aims to achieve an emic or 'insider's view' (Leininger 1985; Wallace 2005). An emic view is focused on the intrinsic cultural features that are meaningful to the members of a given society, such as queuing in British society (Creswell 1998). Members of a culture have specific knowledge about the setting which is shared with the researcher, so that they come to know and understand the rituals and rules of the sub-culture. The emic perspective is seen as being 'culture specific' and the role of the outside observer is to become familiar with and understand the patterns within this setting (Holloway and Todres 2006; Parahoo 2006). The etic view is defined as the extrinsic concepts and categories that have meaning for the observers, such as annoyance if someone pushes in the queue. The etic view has been described as representing the subjective views of the insiders (Barbour 2008). This is because the researcher is not part of that culture and would produce 'knowledge' about what they saw and heard from an outsider's perspective (Holloway and Todres 2006).

Miller and Brewer (2003) attribute the term 'thick description' being applied to ethnography to Geertz in 1973. It is defined as the detailed accounts that explain the cultural and social relationship from data collected by the research tools such as observation and interviews within the field (Bryman 2007). It gives a clear picture of the individuals and the groups in the context of their culture and is accompanied by an analytical component, in that the researcher gives the reader an ethnographic sense of the experience of participants in the study (Denzin and Lincoln 2000).

3.2.6.   Rationale for using focused ethnography

There are a number of approaches within ethnography. Costello (2001) utilised descriptive ethnography, which centred on the description of cultures or groups, in her study on care of the dying patients. Her findings indicated that care was focused on the physical needs of patients whilst emotional and spiritual care were neglected, with nurses being reluctant to talk about death. Critical ethnography concentrates on power relations, typically examining common-sense assumptions and hidden agendas (Holloway and Todres 2003). The

approach drawn on for this study was focused ethnography which developed as a method for analysing health research (Morse and Field 2002).

Focused ethnography developed within descriptive ethnography and has utilised the same principles (Morse and Field 2002). The only differences have been the narrower focus of the topic being studied and shorter stays within the setting. Similar to descriptive ethnography, it has been used by health professionals to improve practice or understand illness because it has enabled them to address specific aspects of the selected research topic (Aamodt 1991; Morse and Field 2002). It has also allowed participants to be connected more broadly in that they may not necessarily be from the same community or social setting but share the same 'culture' through a common illness or health experience (Knoblauch 2005; Morse and Field 2002).

It is assumed in undertaking focused ethnography that the researcher, prior to entering the field, would have gained an intimate knowledge of it through experience or substantial preparatory work. This allows the research topic to be determined prior to data collection rather than emerging during data collection and analysis (Muecke 1994). Consequently, shorter, more intense visits and observations are permitted (Knoblauch 2005). A drawback of focused observation is that such visits restrict opportunities to observe events that arise spontaneously, which might be encountered in observation conducted over longer periods (Morse and Field 2002). Knowledge of the area is also used to alert the researcher to any sensitivities in respect to practices within the culture. This knowledge can be used to adapt to the setting and thereby create minimum disruption to the interactions that occur (Lofland and Lofland 2006; Hammersley and Atkinson 1995).

Focused ethnography was therefore chosen for a number of reasons. It enabled the culture of breast screening to be explored. This was considered to be important in understanding the women's experience of breast screening and the influences upon participation that they would be exposed to. Observing women undergoing breast screening would also permit a picture of the culture to be explored at first hand as well as recording their narratives. This was regarded as significant since it was not just the women who were part of that

culture but also those who performed breast screening as well as those who supported the women – the allied-professionals and paid- and family-carers. Focused observation was necessary because through my previous experience of the area I recognised that the women's world was complex. As documented in section 1.5, where each woman resided, her day time activities and her contact with the health services (including the breast screening centre) would be different from the next woman. Furthermore, these settings were overseen by different organisations which included the NHS, health and social care services, and private and voluntary sectors, and would involve contact with allied-professionals, paid and family-carers who worked with and supported the women. This explained the need for multiple settings. My previous experience of the area alerted me to the fact that it would have been impossible to spend long periods of time in all the settings; whereas spending limited periods in a number of settings would allow me to construct a representation of the experience of breast screening across the LD sector (Morse and Field 2002). Focused ethnography was also permissible because I had been working in the area previously and had built up what Knoblauch (2005) called substantial preparatory work. Through such preparatory work I had identified a number of sensitive issues, including how to interview people with LD and issues of consent, within this population. Therefore before entering the field I could reflect on how to adapt my work in order to deal with these issues. I believed that only by understanding the culture could the questions about the women's experience and the factors that influenced their decision to go to breast screening be answered.

3.2.7.   Within the tradition of ethnography

Having justified using focused ethnography, this section outlines the differences between focused and traditional ethnography. The main difference from traditional ethnography is that the focused ethnographer is familiar with the area they are going to study, which was usually obtained through experience of preparatory work (Knoblauch 2005). The preparatory work also enables the focused ethnographer to undertake shorter and more focused observations than traditional ethnographers. This is because the previous knowledge obtained about the topic means that there is a clearer focus on relevant issues from the

outset. As stated earlier, a drawback of focused observation is that these shorter visits restrict opportunities to observe events that arise spontaneously.

Another difference between focused and traditional ethnography relates to the settings. Traditional ethnography such as that undertaken by Mead (1928), Malinowski (1922) and Patrick (1973) involves one setting whereas focused ethnography allows the researcher to use one or multiple settings. As discussed above and in section 1.5, the woman's world was complicated and this justified the need to observe in multiple settings as opposed to the single setting found in traditional ethnography.

A similarity with that of traditional ethnography is the use of key informants. Traditional ethnographers will often have key informants who enable them to infiltrate the culture they wish to study and this is no different in focused ethnography. Again traditional ethnographers often use gatekeepers to access participants as do focused ethnographers (a discussion about gatekeepers can be found in section 3.5.2.). Focused ethnography does not deviate from traditional ethnography regarding choice of data collection methods, which are outlined in the next section.

3.3.   Part Two: Research methods

Having discussed the rationale for employing a qualitative research design and utilising focused ethnography as an approach, this section expounds the rational of the data collection methods adopted, as well as considering ethical issues and the nature of the sample. The tools chosen to collect data did not deviate from those commonly used by ethnographers – observation, interviews and field-notes.[2] Theory is first discussed before going on to discuss the research process and how I applied the theory to the process, including the pilot work. Where appropriate a discussion about reflexivity will be deployed to

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[2] In this and the following chapters, quotations from interviews are placed within double inverted commas and indented; extracts from observation notes are placed within double inverted commas inside a box with a broken border; extracts from field-notes are placed within double inverted commas inside a box with a continuous border.

demonstrate my part in the research process. Preliminary observations on this theme are now offered.

3.3.1.   Reflexivity

There is a need to address the process of undertaking qualitative work through reflexivity because I, 'the researcher', am part of the research process, as opposed to purporting to be a detached observer in a value-free, objective enterprise. For this reason, critical reflection must be undertaken to provide the reader with sufficient information about the researcher so that the transparency of the findings can be evaluated.

Reflexivity is considered to be a central concept in social science research and has been defined as the researcher's impact on the world they have studied. It reflects their understanding of how their experiences and assumptions might have affected the research process and its outcomes (Hammersley 1990; King 2004). This is in contrast to positivistic schools of thought where the term may be limited to identifying personal bias in research experiments or surveys. Rather than being a separate dimension, reflexivity should be considered an integral element of the researcher's data, heightening the need for them to be highly self-aware and conscious of their role (Lipson 1991; Hammersley and Atkinson 2007). This has led to the suggestion that cultures under study cannot be captured purely on their own terms but must succumb to the application of the researcher's lens (Cutcliff and McKenna 1998). In this study, the concept of reflexivity is valued insofar as it acknowledges that the experiences, knowledge and the cultural context within which the research took place had an influence upon and shaped the research process. The reflexive process was captured within the field-notes and discussions with peers and supervisors. The reflective accounts that follow are an attempt to be transparent about aspects of the research process that may have influenced the findings reported in this study. The first account can be found in Chapter one, where I outlined my personal motives for undertaking this study.

3.3.2. Observation

Observation is a process whereby researchers watch and record the behaviour and actions of others within a specified environment to help them understand the culture they are studying (Bryman 2008; Flick 2009). Through observation the researcher builds up 'thick description' of the area under study and this can be validated by participants through conversation, interview or data generated by other means (Hammersley and Atkinson 1995; Wallace 2005). Observation provides access to different sorts of information and has a number of advantages and disadvantages (Bonner and Tolhurst 2002; Hammersley and Atkinson 2007). Advantages include allowing the researcher to see and hear how people act at first hand rather than relying on their reports and justifications for their actions (Bryman 2007). It also permits the researcher to capture multi-dimensional information insofar as it can account for the situation, people and activity under consideration (Mason 2002). Since not all phenomena can be observed, it is necessary to employ interviews to seek out additional information. Disadvantages include bias, in that the observer will participate in collecting information and potentially influence the process of those being observed (Wallace 2005). Monitoring this is imperative and field-notes and reflexivity can be used to document feelings that might compromise the trustworthiness of the data (Estabrooks 1987; Lee-Treweek 2000; Morse and Field 1996).

Observation may take a number of forms but it generally consists of participatory (taking part) or non-participatory (not taking part) where the observer can be overt (where the participants know they are being watched) or covert (in that the people being observed do not know that they are being observed or are part of a research project). Data collected during the observations can be structured, having a framework or schedule, or unstructured where there is no such framework or schedule (Bryman 2008).

Covert observation is rarely used because bodies such as the Central Office for Research Ethics Committees (COREC) which grant ethical permission for studies to be undertaken make it clear that permission to undertake covert observation would rarely be given (Miller and Brewer 2003). Permission is

seldom granted because informed consent to observe is not permissible prior to observation and participants who are debriefed afterwards often feel deceived (Sanger 1996; Wallace 2005). When the researcher is also a practitioner they have a duty 'to do no harm' when observing (Field 1991, Nursing and Midwifery Council 2008). Overt observation circumvents most of these ethical issues because informed consent is in place from the start (Wallace 2005). For the researcher, the disadvantage of overt observation is that the behaviour of the informant may be changed because they know they are being watched, although the effects are diluted with the passage of time (Bryman 2004).

The researcher also has to make a decision between participatory or non-participatory observation (Bryman 2008). Participatory observation is where the researcher participates in activities and by this is privy to a wealth of knowledge to which the non-participant observer is not (Denzin and Lincoln 2000; Tedlock 2000). The advantage of this method is that it has been found to cause less disruption and enables the researcher to tap into aspects of the culture that they may have missed by interview alone (De Walt and De Walt 2002; Lipson 1991). Participants also feel more comfortable and freer to talk openly if they are familiar with the researcher, which has been found to increase the validity of the information acquired (Tedlock 2000).

Disadvantages of participatory observation are that there is less objectivity and data can be affected by the experiences, attitudes and feelings of the observer (Miller and Brewer 2003). There is also the potential for the researcher to 'go native' and become too familiar with the informants in which case the trustworthiness of the information that is collected can be threatened because of the lack of impartiality (Bonner and Tolhurst 2002; Hammersley and Atkinson 2007). Although non-participatory observation is regarded as being less likely to distort the informant's story or picture of reality, there is a possibility of misunderstanding or omitting important aspects of the setting or behaviour because the researcher is distanced from the situation that is occurring (Denzin and Lincoln 2000; Flick 2009; Hammersley and Atkinson 2007). Either way, the researcher has to make sense of the situation and will be guided by their own experiences, attitudes and feelings: again field-notes and reflexivity can be employed to log this (Morse and Field 1996).

Another decision that has to be made is whether to use a structured or unstructured format. Structured observation uses a schedule which ensures that each informant is observed on the same behaviours over the same length of time (Morse and Field 1996). This method ensures consistency across the observations, although it reduces the flexibility of the observation and tends not to allow for novel behaviours to be recorded. Where novel behaviour is encountered the observer may have to interpret the coding system (Bryman 2008). Structured observation has been identified as being particularly useful when specific behaviour needs to be studied in different settings (Mason 2002). In contrast, unstructured observation does not use a schedule but allows for the entire interaction to be described and hence is more flexible. However, it is inevitable that some information will not be collected or recorded because every aspect of an interaction cannot be captured (Bryman 2008).

Irrespective of the type of observation chosen, access to the field is needed to gain insight into the emic perspective. Access to some communities, such as travellers or street people, has been identified as notoriously difficult (Hammersley and Atkinson 1995; Wallace 2005). Reasons for refusal of access include the disruptions an observer will have on the area and as well as how the merits of the research project are perceived in that area (Flick 2009). Access for observation has been found to be easier when there is a shared understanding of the aims of the research, where the researcher has good rapport with gatekeepers and is known to have an interest in the area (Bonner and Tolhurst 2002; Pope and Mays 2006; Wallace 2005; Walmsely and Johnson 2003). Prior to entering the field, it is advisable that the researcher builds up rapport and explains their presence to those involved (Sanger 1996). Despite this, it is also not unusual for researchers to be welcomed and then rebuffed from the areas they have accessed (Wallace 2005).

Bryman (2007) has suggested that undertaking observation exposes a researcher to a rich environment filled with a great deal of 'noise' from which they are expected to derive some coherent meaning. It is therefore important that the researcher fits into the environment when observing and that they maintain some impartiality towards what they are observing so that they can decipher the social world objectively (Spradley 1979). Ideally the researcher

should have some awareness about the influence they will have on the setting, such as the views they hold (Wallace 2005). This is pertinent in focused observation where the researcher has a preconceived idea of the field they are entering due to their prior knowledge. It is important that feelings, views and knowledge about what is observed are monitored, which is where reflexivity can ensure data integrity.

Undertaking observation with people with LD requires special consideration. Spending time with participants is imperative in order to build up rapport and alleviate any anxieties (McCarthy 2001; Nind 2008). However, some people with LD are isolated due to their limited social capital (social networks and contacts). This can lead to problems such as readily accepting researchers as their friends even after only one meeting, simply because someone has taken an interest in them (Knox and Hickson 2001; McCarthy 2001). Where the research process becomes part of people's lives, as in ethnography, this can lead to dependency and ultimately to a sense of loss and rejection when the research is over. It can therefore be seen as exploitative (Booth and Booth 1998; Northway 2000; Plummer 2001; Rodgers 1999; Stacey 1991). These issues require consideration when working with people with LD.

Observation was used in this study because I believed not all knowledge could be articulated or reconstructed in an interview situation. This was pertinent when working with people with LD as they have more difficulties remembering or expressing what happened. Thus the observations would support the information gathered from interviews and contextualise the findings. What I set out to observe and understand was the interaction between the women and those who supported them during breast screening. Therefore I wanted to see how the women were prepared for and how they experienced breast screening, as this would identify what influenced their decisions to participate. I also wanted to understand how those supporting the woman prepared her and supported her through breast screening. The observation I undertook was overt due to the COREC and NMC considerations. I undertook participant observation due to the restrictions placed on me by the settings (see below). Because I would be entering a number of different settings, I used a schedule to guide my observations.

### 3.3.3.	Designing and piloting of observation in this study

Mason (2002) suggested that a schedule was useful where specific behaviour in different settings was being observed. For this reason I decided to use an observation schedule. Given the aim of the study was to explore the influences on and experiences of women with LD who were invited to participate in breast screening, what I wanted to gain from the observation was to see at first hand the interaction between the women and those supporting them during breast screening. Furthermore I wanted understand more about how the women were prepared for breast screening and the influences they would have been exposed to. For this reason the schedule was based on the 'what questions': what is said, what is done and what is achieved (Simpson and Tuson 2003). Asking these questions would allow me to capture what led to the appointment, what roles were played during the interaction, what information was exchanged, whether the information was tailored to the needs of the person with LD and whether anything else was needed to support these women. To ensure these questions were appropriate, I piloted the schedule.

Undertaking a pilot observation was considered important because it would alert me to any problems I would encounter when observing within the field. I conducted the pilot work in two settings in which I had worked previously: a day-centre and a care group who supported people in their own homes. Prior to the observation, I had contacted the relevant gatekeepers (the managers) and explained the study to them, highlighting that I was interested in what happened at breast screening and how information was discussed with the women with LD. Both agreed to take part and had informed the staff and clients about the study. I also spent time with the staff and clients over lunch and coffee to allow them to ask me questions concerning the study before I formally undertook my observation. This was useful since it allowed people to get to know me and understand the purpose of my research.

I had planned to spend three half-days in the day-centre but there were no health groups running or therapists working due to staff sickness. After discussing this with my supervision team I decided to spend one half-day observing and during the other two mornings I joined in activities such as drama

and music, and discussed the project further with the staff and women. This was useful as it established rapport with some of the potential participants and enabled me to reflect upon how I could use my schedule to record the actions and conversations that I was party to.

Prior to going in to the field with the other care group I highlighted the importance of trying to observe activity around breast screening. Although they had no one going for breast screening, they were preparing a woman for cervical screening and had two people about to attend a doctor's appointment. They invited me to all these and arranged for me to visit a woman who had experienced breast cancer since they felt she would be a good candidate to take part in the study (although she subsequently declined to do so). Again I discussed this with my supervisors and they believed that these activities were relevant and would help with piloting the schedule and contextualising the field. They also warned that I might have to broaden the observation to look at general health interventions because of the limited opportunity to observe the specific topics of breast awareness and breast screening. Acting on their advice I spent two mornings and one afternoon with the care group and piloted my observation schedule during that time.

From this experience, I appreciated that I would have to rely heavily on the gatekeepers to inform me and invite me to discussions about breast health and breast screening appointments. I also realised that I might not be able to observe as many examples of preparation for breast screening or accompany the women to breast screening. Nevertheless, although observing breast-related issues was a problem during the pilot, during the fieldwork I was able to observe discussions about breast awareness and see women with and without LD undergo breast screening.

From the pilot work, I learned that I needed to have some prompts, such as who led the appointment and whether the woman was involved. This helped to refine the main points of the interaction that I wanted to capture. The schedule used for the study is contained in Appendix 1. In addition, I had to think of ways to record what I had observed. I memorised the key headings and jotted notes on bits of paper, such as phrases or keywords under these headings. I also

went to the toilet to write notes or wrote them immediately after appointments. I took this approach because Bryman (2008) suggested that taking a notebook often made participants self-conscious which was something I wanted to avoid. This was confirmed by those who had taken part in the pilot study.

The gatekeepers felt more comfortable describing me as a 'volunteer' rather than as a researcher. This title was seen to give me some boundaries in that the women with LD understood it since they were used to volunteers and knew I was not a member of staff. Furthermore staff would not ask me to lead activities. The gatekeepers also preferred me to participate in activities because this was less distracting for the other clients. This was important because people with LD have been found to have shorter attention spans and tend to wander off during activities so if I had absented myself from the activity I might have been a distraction (Clare and Gudjonsson 1993; Tully and Cahill 1984). Since women with LD present a higher incidence of mental health problems (approximately 30-50% higher than the general population), being part of the activity did not exacerbate existing mental health problems such as those with paranoid thinking, where the person believes they are being persecuted and frequently experience a feeling of being watched (Smiley 2005). One particular encounter (see below) alerted me to the importance of becoming a familiar figure and participating in activities.

"..I had sat out of 'music' as there was not enough room. Patsy a woman with LD moved away around twenty minutes before the end of the session. She spotted me and then engaged me in loud conversation about my green boots and asked if I was checking up on her like the police did. This was distracting for the music group, and caused Pasty some distress thinking she was in trouble so we went for an early coffee." (Observation1, pilot day-centre, page1)

"...The encounter with Patsy made me realise I need to participate as Patsy was not familiar with me. Will have to try and reinforce this in future. I also need to take notes away from activities – this is something to think about – hadn't thought about the police aspect!" (Observation1, pilot day-centre, page 2)

Another area the pilot work made me think about was how I explained my presence to others, such as professionals when I accompanied the women to appointments. I decided to explain why I was there to the health professionals and would explain that I was a PhD student before seeking permission from them to observe the appointment before the consultation commenced. On all occasions the health professionals were interested in the study and consented to the observation.

3.3.4.   Observation for the main study

Observation was conducted on nine participants, three women with LD, two paid-carers and four allied-practitioners. In total, seven observations were carried out, four discussing breast awareness and three observing breast screening. My original proposal was to observe each participant on three occasions. However, as the pilot work demonstrated this was not possible. The observations and post-observation discussions lasted approximately 45 minutes. My visit to the Breast Screening Centre (BSC) lasted four hours as I was shadowing one woman, Julia. Three observations were in the BSC (two at the main screening centre and one in a mobile unit). The other four observations were carried out in the woman's home. Three observations were carried out jointly with women and allied-practitioners who were participants in the study.

I undertook all observations prior to formally interviewing the participants. When undertaking the observations for the main study, I used what I had learned from the pilot observation. In all areas where I was permitted to observe, I was introduced by the gatekeepers as a 'volunteer'. I was asked by the gatekeepers to participate in activities, for example, getting scales for the nurse or joining in the discussion about breast awareness, since this would cause minimal disruption to what was going on. Access to the participants and the settings was always negotiated through the help of gatekeepers and, prior to me observing, the gatekeepers let the staff and clients know about the study. Before observing I met all the participants, with the exception of those in the main BSC.

I had not met the staff in the main BSC before the observations but had telephoned in advance to introduce myself. This was because the staff there were 'busy' and preferred to meet me on the day. Nor had I previously met the woman (Julia) whom I shadowed in the BSC. For these reasons when I arrived at the BSC I introduced myself to the staff during the morning meeting and explained what I was doing. Similarly when I was observing the allied-professionals at the BSC, the staff said they would ask the women if they were happy for me to be present. I would then be given time to introduce myself and explain my study to them. However, I only observed one woman (Julia) undergo breast screening. Because her mammogram was suspicious, indicating a possibility of cancer, I accompanied her through further mammograms and tests. Consequently I was exposed to all the different procedures and the staff who had volunteered to be observed and interviewed.

When undertaking observations, I always dressed smartly in black trousers, a shirt and jacket, although I tended to remove the jacket to appear less formal. I always made it clear how many visits I would be making in order to set clear boundaries and counter potential feelings of loss. I disclosed to all participants that I was a nurse and a student researcher undertaking a piece of research as part of my University course. I did so because a number of the areas already knew me and I felt that I should be honest with the participants. Although the

> *"...After explaining my study to Wendy she said it was 'good I was trying to help women like her who were nervous about accessing breast screening'. Wendy was not disturbed about me observing what she and the nurse were doing she said she had enjoyed it." (Observation1, Wendy and Clary, page1)*

allied-professionals and paid and family-carers may have been less perturbed about me being a nurse, nurses can be seen as 'authority figures' by people with LD (Swain 1998). No problems were perceived from the women with LD, and one woman Wendy (below) positively enjoyed it (see below).

No problems were detected with the paid-carers, although I perceived problems with the mammographers in the mobile unit. When I accompanied Fergi (paid-carer) and Annie (women with LD) to breast screening in the mobile breast unit,

I explained my presence to the mammographers and they were happy for me to observe. However, after they had finished they debriefed me regarding the decisions they made whilst I observed them (see section 4.6.3.). This allowed me to see the anxieties that some participants had about me observing them and alerted me to how I was perceived. Despite this, they were also keen that I went to the main unit and observed there, and I was able to tell them I had arranged this.

During the observations I took mental notes, made trips to the toilet or moved away briefly from the activity and scribbled notes or key words on to the paper I kept in my pocket. This acted as an '*aide memoire*' of things that happened. After the observation I transcribed my notes on the same day onto the schedule in a Word document and replaced their real names with pseudonyms. I acknowledge that, despite the notes being written the same day, some aspects of the interaction would be lost. Furthermore, as Barbour (2008) noted, all records are open to interpretation and this has to be acknowledged by the researcher. Given the constraints placed on me in the settings, I believe that my approach was appropriate, as it met the needs of the participants and the setting. As with any observation undertaken without being video recorded, I acknowledge that some information would be lost. After every observation, if I was unclear about something I would ask questions about the issues I needed more information about and where possible clarified this further within the interview. I believe that this was an appropriate way of getting a sense of the participant's perspective on what happened and to validate my own interpretation of what had transpired.

What I took from the observations was a sense of how information was exchanged and the skills needed to discuss breast screening and breast awareness with women with LD. I also gained a better understanding of the process of going for breast screening for women with and without LD, the roles of those involved and the journey for the woman from the letter of invitation to mammogram.

3.3.5.   Reflexivity on the observation

Most ethnographers enter the field as naive observers (Aamodt 1991; Wallace 2005). This claim did not apply to me since I drew on focused ethnography for my study. This meant that I required an awareness and understanding of the area, which posed a number of challenges due to my insider knowledge. The strength of having such knowledge was that I was granted access more easily, because people knew and trusted me. I was aware of many of the protocols, such as not being offended if one of the people with LD came up and kissed me or swore. I also knew when to remove myself from an area when other people with LD were getting upset. I appreciated that sometimes starting the interviews or observation might take longer, to carry tissues for runny noses and the importance of checking things were still ok with the participant. I was conscious that I would have to be prepared to overcome my shyness when participating in activities such as singing or dancing. Such matters may appear commonsensical, but are important and not documented in textbooks.

A negative aspect of being an insider was that I had to ensure I did not dismiss something as unimportant because I was familiar with the area. I also had to carefully observe my boundaries since I was a 'volunteer' not a member of staff. This meant having to manage expectations, as I was meant to be observing and learning. I also had to avoid 'going native' as this could have had impacted on the trustworthiness of the information collected (Bonner and Tolhurst 2002; Hammersley and Atkinson 2007). Acknowledging that my insider knowledge exerted some effect when gathering and analysing data, I monitored any assumptions or feelings within my field-notes and discussed issues with my supervisors (Bryman 2008; Denzin and Lincoln 1994; Hammersley and Atkinson 2007).

I had to be mindful about my relationships in the field because I would become part of my participants' lives through observation which would rekindle 'old friendships' (Hammersley and Atkinson 2007). In the LD field this is particularly pertinent: the dependency, the sense of loss and rejection that some participants feel when research is over, had to be minimised (Booth and Booth 1998; Northway 2000). My belief was that this was not just relevant to people

with LD but to all those who participated in the observational research. To address this I was always precise about my purpose and stated clearly the number of times that I would observe. This did not mean that I was cold or clinical towards my participants but I was aware, especially with the women, of the need to set clear boundaries. Despite this there are always areas of uncertainty that develop within the relationship between the researcher and the participant, especially in healthcare research (Lincoln and Guba 1985). This was brought home in the two following incidents.

When observing Julia undergo a breast core biopsy (removal of tissues from the breast) she reached for my hand and I held it throughout the procedure. When another participant, Heather, became emotional about what might happen to her daughter when she died, I switched off the tape, touched her hand and listened. These gestures were offered in full knowledge that I should be impartial when undertaking observation or interviews, but not offering such gestures also went against my nursing instinct. Eide and Kahn (2008) suggested that where such conflict arose between the research and nursing roles, that the nursing sentiment should prevail and that this should not be ignored by nurse researchers. This was also echoed by my supervisors.

Within my reflections I believed that holding Julia's hand was something I would have done if I had been employed as a nurse and it was something my participant welcomed. With Heather I concluded that switching off the tape and listening to her was the most appropriate action to take as enquiring further into this would have steered me into an area that I was uncomfortable with and unqualified to pursue. In doing so I believe I acted compassionately, responsibly and professionally.

During the observation I questioned whether I should have intervened during an observation of Annie (woman with LD) going for breast screening. During the procedure I was surprised about how little reassurance the mammographers gave Annie and the amount of pushing and shoving there was to get Annie into position. Both Fergi (paid-carer) and myself attempted to give her reassurance. In the subsequent follow-up interviews, Fergi was annoyed that the mammographers had not let her stand alongside Annie to give her reassurance

whilst Annie was just glad it was over. I acknowledge that there was a need for some manoeuvring of Annie into position and that this could have looked more brutal than it was. What was more disturbing was the lack of encouragement given to Annie by the mammographers. I accept that this may be because Fergi and I were signing and speaking to Annie throughout the procedure. I also acknowledge that the mammographers may have been inexperienced with working with this clients group. But I wondered whether I should have intervened. In discussions with colleagues they suggested that this was a difficult situation and there were no right or wrong answers. This supports Tuffrey-Wijne, Bernal and Hollins (2005) who state it is often difficult to know when to intervene. Having reflected on this, if I was in the same situation again I would request more support be offered to Annie. By declaring this, I believe I unintentionally let Annie down.

Observation has been found to lead to feelings of apprehension, isolation, loneliness and frustration, all of which can distort the analysis of data (Hammersley and Atkinson 1995; Lofland and Lofland 1995). To counteract any problems of distortion of data it has been suggested that the researcher should acknowledge and document any feelings experienced during the research to ensure the trustworthiness of the analysis and data (Morse and Field 1996; Silverman 2000). I found observing the most difficult part of data collection, as one is essentially intruding. Even by writing this I have declared an apprehension to observation and acknowledge that this would have had some impact. An example of how this intrusion surfaced was when I observed Fergi and Annie going for breast screening. It was only the second time I had to explain my presence and I was apprehensive knowing that this was such an important opportunity for me in this study. Although the mammographers allowed me to observe, when they had taken Annie's mammograms they approached me to explain their actions. This was useful for me since it clarified the areas I was unsure of, but it also identified that my presence had impacted on the situation. Documenting my feelings and those of others after the observation in my field-notes and discussing this with my supervisors and other PhD students was a way of correcting any potential preconceptions.

3.3.6.   Interviews

An interview is a means of dialogue characterised by a two-way conversation. It goes beyond the spontaneous exchange of views that is found in everyday conversations because it aims to gather data from participants, the nature of which has been determined by the researcher (Flick 2009; Gilbert 2004; Hammersley and Atkinson 2007; Millerand Brewer 2003). Interviews also connect the researcher and participant to help the former understand the world from the perspective of the latter (Johnson 2000).

The advantage of interviews in qualitative work is that they are flexible. The less structured the interview, the more flexibility is granted to the interviewer to check, probe, prompt, clarify and confirm information, while allowing the interviewee to clarify the meaning of the questions posed (Flick 2009). Where the interviewee deviates from a topic, cues such as body language can help the researcher decipher whether they have found it hard to discuss or did not understand the topic (Morse 1991; Taylor 2005). This is relevant for people with LD (Booth and Booth 1996). Interviews are also seen as being more inclusive for people with low literacy skills, such as those with LD, since it dispenses with the need for them to write responses or seek help to write them down (Carr and Hollins 1995; Davies and Duff 2001; McCarthy 1998). Furthermore, they can be combined or triangulated with other methods of data collection (Bryman 2004; Holloway 2005).

Disadvantages of interviews include that they are considered time-consuming in terms of travel to and from the place of interview and transcription which is labour intensive (Bryman 2008). In practical terms, interviews should be conducted in private as interruptions may have an impact on the quality of the interview (Mason 2002). It is also difficult to have total anonymity as the researcher will know the person's name (Bryman 2008). Participants may also be less forthcoming in interviews, or simply supply answers they think the interviewer wants to hear, especially if the topic involves sensitive or embarrassing information (Flick 2009; Wallace 2005). The participant can also be influenced further by the age, sex and dress of the interviewer. Often this can be linked to the researcher being seen as an 'authority figure' (especially in

people with LD) and this may compromise the quality of the interview (Swain 1998).

A common issue concerning interviews is whether to take notes or make a recording. Advantages of recording the interview are that there is a permanent record of what was discussed and aspects such as the tone of the questioning and response allow for deeper examination to take place (Flick 2009). The disadvantages are the cost of equipment, concerns over it not working and that the act of recording may put interviewees off. Bryman (2007) commented that often interviewees say more once the tape has been switched off. Transcription of the tapes also enters into the argument. Transcribing the tapes can be time-consuming. Consequently researchers have to decide whether they will transcribe the tapes or whether they will get the tapes transcribed (which can be costly). A discussion about transcription can be found in Section 3.3.11. Decisions also have to be made about what is transcribed – for example, every 'er' and 'um'; and if pauses are transcribed the decisions needs to be taken about whether these should be timed. Note taking is an alternative to recording, but cannot capture all that was said hence some data will be lost. Moreover, the copious writing of notes may be a distraction for the interviewer and the interviewee (May 1991).

Interviews used in qualitative work are generally semi-structured or unstructured. Unstructured interviews are characterised as being informal, allowing the interviewee to respond freely to an initial question posed by the interviewer whilst giving flexibility for the interviewer to pick up on points of interest (Bryman 2004). This is counteracted by variation in the phrasing and sequencing of questions from interview to interview, making comparison difficult. Furthermore, this type of interview has not been found useful when interviewing people with LD because they tend to say less when open questions are used, or respond in a single word, short phrase or the odd sentence (Booth and Booth 1994; Booth 1996; Fritzley and Lee 2003; McCarthy 1999). For these reasons, unstructured interviews were not considered for this study.

Semi-structured interviews are characterised by the researcher having a clear focus with a list of questions or specific topics to ask the interviewee (Bryman

2008). This counteracts the variability of the phrasing and sequencing of questions from interview to interview. However, the structure can reduce flexibility of questioning. Sometimes interview schedules are drawn up to help the interviewer to navigate the interview. Schedules have been found to enable the researcher to be prepared and have the situation under control, but also allow for them to follow up new leads (Kvale and Brinkmann 2009).

Taylor (2005) has suggested that the first question on any interview schedule or interview should be aimed to relax the interviewee and focus on their background, before moving on to more complex or sensitive questions. The questions asked should reflect the language used by the interviewee rather than jargon and be tailored to the communication ability of the participants (May 1991; Milne and Bull 2001; Stalker 1998). This is pertinent to interviewing people with LD since they often have difficulty in comprehending questions posed in an interview context and tend to need questions clarified. They therefore find shorter and more focused questions easier to answer (Booth and Booth 1994; Gilbert 2004; McCarthy 2002; Swain 1998). All participants have the potential to be poor historians and interviewers need to factor in the ability to ask the same question in different ways to gauge the consistency of the response (Atkinson 1997, Booth and Booth 1996; Rodgers 1999; Stalker 1998). A criticism of semi-structured and unstructured interviews is that, because that they are not standardised, there may be different questions asked with a different emphasis. Questions may not be in the same order, which may impact on trustworthiness of the data (Flick 2009).

3.3.7. Interviewing people with LD

There are a number of considerations when interviewing people with LD. Given the variability in language skills, interviewers have used a number of techniques to engage people with LD, including using family photographs to open up or carry forward dialogue (Booth and Booth 1994, 1996). This is important since interviewers ask questions about views and feelings and many people with LD have limited experience about being asked for their opinion (McCarthy 2002; Taylor 2005). However, McCarthy (1999) used interviews in a different way, employing them to verify her knowledge about the women she had worked with

as a sex education officer for her study. For those people with LD who struggle with verbal information, supplementary pictorial information to support the verbal content has been advocated (The Department of Health 2001b; McCarthy 1998; McCarthy and Millard 2003). There are a number of tools available such as line drawings (McCarthy and Millard 2003), photos (Booth and Booth 2003) symbols (Levi, Kimpton and Sim 2006) or Talking Mats (Brewster 2004). There has been debate about the best type of pictorial prompts to adopt. Many of these tools have drawbacks: for example, symbols have been criticised because recognition of the symbols need to be taught; photographs are only relevant to that person; whilst Talking Mats requires interviewers to be trained in their use (Levi 2006; Poyner 2006; Siggs 2008, personal communication).

Another issue raised within discussions about interviewing people with LD is the discussion of sensitive topics. Where sensitive issues are being examined, a same-sex researcher is often preferred because it reduces anxieties (McCarthy 2002; Rodgers 2001). Other ways to minimise these problems is allowing the informant to choose where they want to be interviewed or offering to answer questions posed by the participants (Chatzifotiou 2000; Swain 1998).

3.3.8.   The choice of interview design in this study

In this study I used semi-structured interviews to collect data because they were seen as being more flexible and allowed all participants, especially women with LD, to clarify questions. They also enabled me to follow up questions or pose a question in a different way to clarify the participant's response. Again, this was most useful for women with LD. I could also incorporate information derived from the observation or through informal chats with the women prior to interview to clarify points or open up conversations. Having some structure also provided reassurance of control for me, especially exploring sensitive issues which could be difficult to negotiate spontaneously. Having topics and questions prepared in advance also assisted me in delivering the questions more clearly. It enabled me to source pictures about the topics of the questions prior to the interview to aid understanding of the questions by women with LD. In order to capture the richness and breadth of participants' responses, I decided to ask participants if I could tape record the interviews. This was supplemented by written field-notes

(a discussion about field-notes can be found in section 3.3.13.). Field-notes were used because they allowed me to reflect and acknowledge the elements in the interaction that could not be extrapolated from the audible exchange of information.

3.3.9.   Designing and piloting the interview in this study

The design of the interview involved considerable preparation. The interview schedule that I drew up was based around the research questions and the gaps identified by the literature review, for example the woman's experience of breast screening. As the interviews took place after the observation I decided that anything outstanding that needed clarifying from the observation could be explored during the interview. I used topic areas to act as an *aide memoire* during the interview and also formulated some questions in-advance, especially for the women with LD, to ensure the questions were clear. Such clarity was important as I believed this would help the participant to understand the questions being posed. The central content (see below) was similar for all participants (women, allied-professionals and paid- and family-carers).

All interviews started with a topic about the interviewee, aimed at relaxing the participant and giving them confidence in answering the later questions (McCarthy 1999). For the women's interviews, the first topic of the schedule asked the participant, 'Can you tell me about yourself?'; for the allied-professionals and paid-carers, the first topic asked, 'Can you tell me something about your role?'; for the family-carers I would ask ,'Can you tell a little about yourself?'. This reflected the circumstances of the person I was interviewing. The interview then moved onto topics designed to answer the research questions. On completing my schedule I asked all participants if they wanted to add anything or ask me questions. I had found this useful in previous work as often they spoke about related issues or came back to points raised by the interview.

The main content of the interview was similar for all participants. After the opening question, the next topic explored with the women was how they kept themselves healthy and this included prompts about diet, exercise, smoking and

drinking. The schedule then moved on to asking them about how they kept their breasts healthy, posing questions such as, 'Do you know how to keep your breasts healthy?' After ascertaining whether they had been for breast screening, I asked what this was like and how they had made their choice to attend. This was because I wanted to find out what their experience of breast screening was from their viewpoint. I used direct questions because both my previous experience and the literature suggested this was most effective. The schedule was similar for the people who supported the women (allied-professionals, paid and family-carers), although focused on the women's experience of breast screening and the support they provided for them when attending breast screening. It was also less structured than the women's interview, but the same topics were used to guide me through the interview. I also asked more open questions, such as, 'Can you tell me about the time you accompanied a woman to breast screening?'. The aim of the interview was to explore their understanding of breast screening, how they approached breast screening with the women, how they supported the women and what influence this might have on the women they supported decision to attend screening. I believed that exploring these topics would help to unravel what may have persuaded the women to participate in breast screening and get a better understanding of the women's experience.

For the women, I devised pictorial prompts which drew on my previous work while FAIR and Down's Syndrome Scotland allowed me to use pictures from their breast screening and breast awareness literature (examples can be found in Appendix 2). The value of using these pictures was that they had already been peer reviewed by people with LD and so were seen as being an accurate reflection of the topic under discussion.

Having devised the interview schedules and pictorial prompts, these were piloted. The pilot work involved two women with LD, three allied-professionals and two paid-carers. The interview was not piloted on family-carers because of the difficulty of recruiting this group. The women who took part in the pilot work had also helped me in previous studies and were used to giving me feedback about my work. The suggestions made about the interview schedule related to changes to the wording of questions. The women suggested using the term

'keeping your breasts healthy' instead of 'checking your breasts', as this was a term the nurses had used with them. One of the allied-professionals I discussed the women's interview with suggested using 'a special clinic to get your breasts examined', and 'where a machine examines your breasts' for the actual breast screening procedure. This input was extremely helpful and reflected what they women had said. The only change to the pictorial prompts was deciding which picture was clearer if there were two pictures depicting similar content. An additional suggestion was to enlarge some of the pictures.

From the pilot interviews with the allied-professionals and paid-carers, changes suggested were to include something about their needs for training about breast-related issues. It was also suggested that the wording be changed from 'care for' when describing the women with paid-carers and allied-professionals to 'support' and using age-banding rather than directly asking the person's age. The pilot work was useful as I felt more confident with the interviews. I also realised that I would need to be more dextrous with the pictorial prompts when interviewing, and so divided them into sections reflecting the interview topics. I also realised that I did not need to use all the prompts and topic areas for those who supported the women, since some issues were covered during discussion of other subjects. Examples of the interviews can be found in Appendix 3.

3.3.10. Conducting the interviews in the main study

In total, 35 interviews were conducted (12 women with LD, 10 paid-carers, 10 allied-professionals, 3 family-carers). Thirty-four of the interviews were conducted in the participant's work place, day-centre or place of residence. One participant chose to be interviewed in my office at the University because she wanted to go shopping afterwards. All interviews were conducted in a private room, although on two occasions there were interruptions from people entering the room by accident. When interviewing I dressed as I had for the observations. I always sat adjacent to the participant and would have the interview schedule on my knee. When interviewing the women with LD I would have my pictorial prompts on a table or on another chair so that the woman and myself could look through them together. I started each interview by thanking

the participant and asking them if they had any further questions about the study. I would also reconfirm their willingness to be a participant and remind them they could opt out at any time without having to give any reasons.

I would then ask the participant if they were willing to be taped, reminding them about the option of taking notes. Fifteen participants declined to be taped (7 women with LD, 3 allied-professionals, 5 paid-carers, I family-carer). Where permission to tape was declined, notes were taken contemporaneously and were read back to the informant to check for accuracy. Reasons for declining to be taped were given by two participants Rita (allied-professional) 'hated' the sound of her voice on tape, while Pippa (woman with LD) had been in trouble with the police and said it reminded her of the police interview. If the participant agreed to be taped, my Dictaphone was placed on the table or chair between the participant and myself. I would then take their consent to be interviewed. A discussion of consent can be found in Section 3.4.4.

The interview always started by asking the participant about themselves and all groups responded well to these questions. For example, Jane (woman with LD) said these questions were 'easy', whilst Clary (allied-professional) said talking about her role helped her to forget it was an interview. This reassured me about the approach I had adopted. The interview then moved on to the other topics (described in Section 3.3.9.) and at all times the pace of the interview was dictated by the interviewee.

During the interview, if I was unsure about the answer I would clarify this with the participant and say things like, 'Am I right in thinking that...', or reflect back what they said. Where I wanted more information I would ask the participant, 'Can you tell me more about ...?' This was done so that I was sure of my own understanding of the answers given and the participants readily provided the information. The following extract featured a typical request for clarification:

> *"DW: so you do the menus?*
> *Veronica [Paid-carer]: yes we do that with them*
> *[the women] we are sort of saying would you like*
> *such and such ..."* (Interview, Veronica, page4)

Throughout the interview I would ask the participant if they were still OK to continue and reminded them that if they did not want to answer the questions that it was all right. When I was taking notes, I would read back to the participant and explain why I was doing this, reassuring them that I wanted to ensure I had captured their views and meaning accurately and to check my understanding as well. Where I was unsure during a taped interview, I would also summarise again to ensure I understood what was being said.

> *"DW: so you have worked here for 4 yrs and you began as a Nursing Auxiliary.*
> *Rita: Yes that's right."* (Interview, Rita [allied-professional], page1)

I used the picture prompts in nine of the interviews with the women. I always told them that I had some pictures to help them understand the questions and asked them if they wanted me to use them. The three women who did not use them nevertheless wanted to look through them. In the interview with Jane she requested to have a look at the pictures although did not use them during the interview. The prompts were typically used to reinforce what I was talking about or when they were unsure of something. In the interview below with Marion, we had been using pictures throughout the interview. She had been for breast screening but needed a reminder about what it was.

> *"DW: have you been for breast screening?*
> *Marion: erm I think so but I'm not sure*
> *DW: Have a look at this picture*
> *Marion: Yes. I went there."* (Interview, Marion, page3)

In order to open up the dialogue with the participants, I would sometimes use information from my field-notes which had been gained when I had initially spoken to them about the study. For example, when interviewing Rona she was very nervous so I asked her if she had been to bowls recently (as she had spoken about this when I recruited her) and this opened up the conversation. Similarly, when I interviewed Margaret (paid-carer) she was also nervous so I asked whether she had heard about her interview for the manager's post and she said she had been successful. Using this format to engage participants in

conversation meant that some responses were not as spontaneous as others but it helped me to relax them in order to gather views.

In order to contextualise what they were speaking about, some participants would draw on experiences from other health interventions. Sandra (paid-carer) spoke about the difficulty of her clients going to the dentist, while Wendy (woman with LD) spoke about her experience in hospital. The concerns they raised were included in the findings as they clearly demonstrated the difficulties faced by the people working in the area and by the women themselves. I believe all participants spoke openly about their experiences. For example, following an interview Ronnie (allied-professional) had been prompted to check on the women she was seeing about their breast and cervical cancer screening status. She then rang to tell me that the two women we had visited during the observation were now going for breast screening.

There were only two interviews that terminated early. When talking to Heather (family-carer) about whether her daughter would go for breast screening when she was older, her eyes welled up with tears. I asked if she wanted me to stop the tape and she said 'yes'. She disclosed her fears for the future, namely her worry over what would happen if she died. Whereas Vera (woman with LD) began putting the TV on and when I asked if she wanted to terminate the interview she said 'yes'. I believed that by asking whether the participants wanted the interview to be stopped was appropriate and upheld the ethical values required of any researcher.

When I had completed all my questions the participants were asked if they wanted to add anything or ask me questions. The women with LD typically asked me questions about whether I had been for breast screening. Questions from the other groups were more about where to get information about breast screening while some asked me to come and give a talk to their staff. After the interviews I would write down any observations I had made during the interview and put them in my field-notes.

Of the 35 participants interviewed, seven were not conducted on a one-to-one basis. In three cases the women requested that their paid-carer were present

to give them support, whilst two paid-carers asked to be interviewed together, as did a family-carer and woman with LD (they both had LD and wanted to support each other). Interviews lasted approximately 25 minutes for the women but ranged from 20-45 minutes for the allied-professionals; for paid and family-carers the average was 35 minutes but ranged from 30 to 60 minutes. Shorter interviews with the women were used to ensure that they stayed focused. Mairi (woman with LD) said that she enjoyed this interview because others had 'gone on a bit'. Interviews with allied-professionals, paid and family-carers were intentionally kept short to make it easier to fit them into their working day. Clare (allied-professional) was pleased that the interview was short as it allowed time to prepare for her next client. The allied-professionals, paid and family-carers were generally more talkative. Vicki (family-carer) spoke for the longest time (one hour) whereas the shortest interview (20 minutes) was Rona (woman with LD) who preferred to answer in short sentences or point to things.

3.3.11. Transcription

There are different schools of thoughts about the transcription of tapes. Silverman (2000) suggests that the tapes be transcribed in detail, follow coding conventions such as symbols to represent length of pauses, interruptions or emphasis, while Strauss (1987) suggested only transcribing as much as is required by the research. I chose the latter. I decided to that I would not code each pause or 'erm' because people with LD often have articulation problems and I believed this would not add to the analysis. Since I wanted an overall view of participants' experience and views hence I chose to look at themes rather than precise re-constructions of how they were articulated.

I transcribed all the interviews myself within three days of the interview. My reasons for transcribing the tapes myself were that it allowed for consistency of transcription and enabled me to immerse myself in these data. When I had tapes transcribed professionally before, many of the transcripts came back with most of the speech labelled as 'inaudible', especially interviews with people with LD. All participants were given a pseudonym and this was used on all corresponding documentation and in the extracts presented in the findings. I transcribed all the speech on to a Word document using the pseudonym to

identify the participants. I transcribed all the conversation and where the speech was inaudible I documented this in the transcript. I also used my notes to identify interruptions and where I had recorded any actions such as the women demonstrating checking their breasts.

3.3.12. Reflexivity on the interviews

Some of the issues – insider knowledge, boundaries of the researcher and my influence on the participants – discussed earlier in relation to the observations, were equally applicable to interviewing. Therefore I have chosen to reflect on different issues arising from the interviews; some issues could also be relevant to the observations.

Within supervision I was asked an interesting question. This was that I did not make a great deal of distinction between the interview techniques used for each group: women, carers and allied-professionals. I acknowledged that I had made a few more adjustments for the women, such as using pictures, but factors such as watching for boredom, body language, different wording of questions and schedule content were in place for each of the groups. For this reason, I acknowledge that there may have been differences but that all participants were treated equally. My defence for this is that I believe that all people are equal and should be treated as such. Each interview is specific to an individual and therefore unique. It will not be able to be replicated, due to factors such as the historical context or rapport with the interviewee.

One significant challenge was the possibility that my colleagues would volunteer to take part in this study. Having worked in the area as a researcher and enlisted their help for different projects, I was aware that in undertaking a study which required me to interview and observe allied-professionals this might occur. Excluding the women, paid-carers and allied-professionals who volunteered for the pilot work (all of whom were used to helping me pilot my work), I had previously worked with or had contact with six other participants in the sample (n=2 women with LD, n=2 allied-professionals and n=1 paid-carer). It was important therefore to ensure I did not take for granted and assume too

much because I had insider knowledge. I also wanted to ensure that they could be critical of the area and I tried to reassure them of this.

I was aware that interviews can induce anxiety, and this was especially pertinent for women with LD who are not used to expressing their opinion (McCarthy 1999). For this reason I was mindful to reassure the women that their paid-carers or parents would not be told the content of the interview. The paid-carers and allied-professionals were similarly assured that their line managers would not be informed. I was also careful about the power balance since my position as a nurse could be perceived as an authority figure by some of the women. I believe that by spending time with the women many of the barriers were broken down for all the participants. An example of this was when the power balance was reversed while spending time with the participants in the different workshops. In these circumstances I became the 'learner', as the women with LD took me under their wing and taught me how to knead bread properly, dance, play the drums and to organise the dining room ready for lunch. This was a humbling position in which to be in but one in which most people will never experience. Through my willingness to participate in activities I believe I gained trust in the settings within which I worked. Another way by which I tried to reduce the power imbalance was allowing the participants to determine the place, date, time and pace of the interview.

A further challenge was my use of pictures in the interviews. I chose to raise this on a training day for researchers. Although tools such as pictures are used when interviewing people with LD, I wondered whether I was putting words into the women's mouths. One research fellow from another University and I corresponded on this issue for several weeks afterwards and I also discussed this issue with colleagues and my supervisors. We all agreed that that the pictures were imperative to assist the women discuss the issues within the interview. However, there was always the possibility that some women were merely acquiescing. Irrespective of whether pictures or questions are used, acquiescing is one of the disadvantages of interviews that the researcher is faced with (Flick 2009; Wallace 2005).

3.3.13. Field-notes

Field-notes are used by ethnographers to record thoughts, experiences and theoretical comments (Gerrish and Lacey 2006). They are defined as detailed summaries about how the interview or observation went, where it took place, whether the participant was talkative and other feelings about the interaction (Bryman 2004). Advantages of using field-notes are that they can act as an *aide memoire* for the researcher and add to the thick description (Mason 2006; Silverman 2006). They can also help the researcher make sense of their feelings and be part of the audit trail for understanding the culture or developing themes (Mulhall 2003). Field-notes can also be used to support the findings and are no longer only reserved for the eyes of the researcher (Bryman 2008).

Disadvantages of field-notes are that much of what is collected reflects the researcher's own interests and what they remember. Consequently, the type of data produced is variable, ranging from description to data that is partly synthesised to ideas for interpreting the data collected (Mason 2002; Silverman 2006). Field-notes may also display little coherence since they record chance meetings, fragments of narrative and description of things that were considered important at the time. Much of what is written is therefore never incorporated into the findings (Miller and Brewer 2003). Although writing the notes after leaving the field may incur problems with accuracy, it avoids the issue of confidentiality if participants ask to look at notes taken contemporaneously (Mulhall 2003).

There is no definitive method advocated for the writing or content of field-notes. This lies entirely with the preference of the researcher (Bryman 2004; Montgomery and Bailey 2007; Patton 2002). In ethnographic research, detailed notes are usually taken initially before the focus is narrowed as the researcher refines their topic (Bryman 2008; Hammersley and Atkinson 2007). How the field-notes are written also depends upon how they are to be used: as raw data to be analysed later; to develop understanding of the field; to document thoughts and feelings; or a combination of all three (Mason 2002; Silverman 2006). Mulhall (2003) suggested that every researcher will have their own way of writing notes, although she employed a structure using headings such as

'people', 'dialogue', 'personal reflective diary'. How and when they are written generally takes two forms: condensed or extended format (Hammersley and Atkinson 2007; Holloway and Todres 2006). Whatever form they take, the preference is to write them up as soon after the events have taken place (Bryman 2004; Mulhall 2003). Condensed records are short descriptions taken in the field during data collection, either through mental notes (those retained in the researcher's head) or jotted notes on bits of paper, such as phrases or keywords (Bryman 2008). This is because it is not always feasible to write the notes in the setting as it can make participants self-conscious. These condensed notes can then be transformed into extended notes after leaving the field where the points jotted down are expanded upon (Holloway and Todres 2006).

3.3.14. Field-notes in this study

I have always used field-notes as part of my work. Because I was comfortable with this tool, I decided against piloting them. Notes were always made when I observed or interviewed participants. Field-notes were used as an *aide memoire* to jot things down after interviews or observations (see below).

> *"Before we started the interview Sandra and Maureen asked if I would talk to the local LD group about my work once it was complete. They explained what the group did and gave me the details of the organiser. There seemed to be a lot of support for the study ... I also thought this would be a good forum to 'test' the themes." (Field-notes, Sandra and Maureen, page1)*

After meeting a client I would reflect on how I thought the meeting went, the date and time we had set to observe or interview. These notes help me prepare for the observations or interviews since I would read over my notes to get a feel of the receptiveness of the participant prior to interviewing them. In the example below I had noted that Pippa (a woman with LD) liked the television programme, 'The Bill'. When I interviewed Pippa she was more hesitant than she had been when we first met so I asked if she was still willing to take part

and that it was all right if she had changed her mind. Pippa clearly stated she wanted to take part. Believing her to be 'nervous', I used the knowledge about her favourite TV programme the Bill to open up the conversation and to try and relax her. This was a successful intervention.

> *"...met Pippa and she was enthusiastic. Date set to re-contact her and provisional date for observation - check with Ronnie. Likes the Bill especially 'Smithy'." (Field-notes, Ronnie and Pippa, page1)*

My field-notes also added to the thick description and the trustworthiness of the data since I would also reflect on my feelings and thoughts about how the interaction went and ideas for themes. Some of my observations and notes were also incorporated into my findings (Chapter 5) to help support or contextualise them. An example of this can be found in section 4.2.4. Tanya (woman with LD) was talking about checking her breasts because she was still worried about cancer. This worry was also identified within the field-notes.

The field-notes I used were condensed notes since this suited the setting I was working in as it meant I could keep things in my head, jot notes or scribble key phrases down unobtrusively on bits of paper to help me remember things later. Once I left the field, I transferred them into extended notes by typing them into a Word document within a day of each meeting. This helped to keep the material as fresh as possible. Having selected the topic I already had a narrow focus. In writing my field-notes I used an adapted version of the structure proposed by Mulhall (2003), incorporating aspects such as who was present, the environment, and dialogue. (See appendix 4). I organised my thoughts under each of the headings to enable me to make sense of the field-notes and to give them some of order (see below). The notes initially were very detailed, incorporating such observations as colour of wallpaper, but eventually narrowed as my ideas and understanding of the field developed. The field-notes fitted into the dataset because they were useful in capturing additional information, pondering on all aspects of data I had been exposed to.

> *"...[People]Mairi's carer Jill made me a cup of tea whilst Mairi showed me into her bedroom as it was private. [Environment] It was a modest room, with ripped wallpaper in one corner. The room seemed to need redecorating? A single bed, one chest of drawers, a wardrobe and a few pictures of her on outings and at a Christmas party. By the window was an exercise bike. Mairi had to move it as she wanted the curtains shut. This took her a while but would not let me help. She pointed at it.[Interest] "My bike." She then got on it and started to cycle. I do this. Every night. I cycle ... vroom. I take exercise.... [Dialogue]"Jill helps me buy it." ... [Reflection]I thought this was very progressive and displayed an excellent working relationship." (Field-notes, Mairi, page 1)*

In the data analysis, field-notes were useful to help with trustworthiness (see Section 3.6.9). This constituted a preliminary point at which information from the interviews and observation could be interrogated and linked in my thinking. When writing my findings, in order to contextualise and support data obtained during the interview and observation, I used some of the text within the field-notes. I believed this demonstrated the utility of having made field-notes.

3.3.15. Reflexivity on the field-notes

When undertaking this study I had some preconceptions about breast screening and remain unsure about its merits. I strongly oppose GPs being paid to ensure women are screened as in cervical screening and for this reason I am more comfortable with breast screening. Similarly, when reading the literature, I reflected on the messages within it, in that most intervention studies seemed to forget that women have the right to say no to being screened. Writing this in my field-notes and discussing with colleagues helped me contain some of these feelings. When undertaking this study I had to ensure that my prejudices did not come through or influence the responses of the participants. Irene (woman with LD) provided testament to this at the end of the interview. She told me she thought it was important women went for breast screening and that I was 'supporting women' like her to go for mammography.

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I presented my convictions for undertaking this work in Chapter 1. My previous research had made me aware that many of the paid-carers had poor knowledge about this area and wondered whether they were unintentionally letting the women down. I was encouraged to take up the baton because I knew of no studies in 2006 that had given a voice to these women on this topic. Given that the trend in health research was to understand services from the perspective of those using them, I believed that this would be a useful and worthwhile study to undertake to fill that gap. As to whether I still believe the paid-carers were unintentionally letting these women down, I concluded this was the case for some. But for others, because of their own convictions or the convictions within the service in which they worked, the answer was more complex than I had originally contemplated.

Hammersley and Atkinson (1995) have made a valid critique of the use of social research for the purpose of advocacy on behalf of particular groups. They have suggested that the results of such research can often be biased and one-sided and have proposed that preference should be given to the broader values of enquiry. In this study, I explored not only the experiences of women with LD but also those of allied-professionals and paid and family-carers who supported women with LD during breast screening. I believe that studying different groups countered the argument that I was taking sides and ensured that I dealt fairly with all informants: the powerful and powerless (Murphy and Dingwall 2003). This is not to deny that my own values, roles and feelings did not play a part in the generation of these data, but that as far as possible these were brought under control through supervision and in my field-notes (Hammersley and Atkinson 1995).

The experiences in the researcher's personal life can have an impact on analysis and data collection (Hammersley and Atkinson 2007; Mulhall 2003). In the last two years of writing the thesis, I have experienced an unusually large number of bereavements. The last six months alone has seen four deaths of close friends and my own mother, who died just before I completed the thesis, whilst my cousin who is younger than me is terminally ill with breast cancer and my brother is recovering from a serious heart attack. During data collection and analysis and writing up the findings I used my field-notes to capture any

emotional responses to the subject matter. Given that the results were peer-reviewed (see Section 3.5.9), I can only assume that my personal experiences did not have a substantial impact on data analysis.

3.4. Part three: Ethical approval and permissions

Any research undertaken on human participants must have safeguards in place to ensure they are protected. Safeguards are needed to ensure participants are protected from, for example, social harm through disclosure of sensitive information or the emotional and psychological issues that arise from being asked personal questions (Cormack 2000).

3.4.1. Ethical principles

It is important that the researcher adheres to the ethical principles which in heath research draws on the four core principles: autonomy (governance of one's own actions), beneficence (doing good), non-malificence (doing no harm) and justice (treating like cases alike), (Beauchamp and Childress 2001). To illustrate how these principles were observed, examples of each principle in relation to this study will be given below.

Autonomy was addressed by ensuring that each participant received a full explanation about the study during the recruitment phase. Reassurance of their right to withdraw at any stage of the study without negative consequences was also explained. Beneficence encompassed the researcher's duty to act in a way that benefits the participant, such as ensuring the participant is treated with respect and dignity (Streubert and Carpenter 2007). I explained to participants that there was no immediate benefit to them but the findings might benefit others in the future.

Confidentiality in a study should not place participants in a position where they are compromised (Beauchamp and Childress 2001). All participants should be guaranteed confidentiality and that no information will identify them. They should also be made aware that what is said (if published) will also be anonymised and this was stated again within the informed consent process (Bryman 2008). In the current study I protected the anonymity of the participants by removal of any information that could identify the setting and I used pseudonyms to conceal identities. I gave all participants and corresponding data a study number and stored it in a locked cupboard with the

list identifying participants being stored separately. These steps were explained to and agreed by all the participants.

In any study, participants could experience harm (physical, psychological or social) and the researcher must try to minimise this. In this study, I explained the research to each participant to try and alleviate their anxiety. I also visited each participant prior to being observed and or interviewed and offered an explanation of the process of the research. I reminded participants that they could withdraw at any time from the study. When observing I was mindful of the women's mental health problems and therefore decided to participate in activities rather than sit at the side observing. I also put in place strategies such as information for support and contacts for the women's aid group in case the women disclosed previous or current sexual abuse during the interviews. Whether the woman took any action after disclosure depended upon her own decision as stipulated by the ethical conditions from the Central Office for Research Ethics Committees (COREC: now IRAS– Integrated Research Application System).

3.4.2.   Ethical approval

As with all research studies this study was subject to ethical scrutiny and approval from a number of different bodies. All research studies undertaken at Edinburgh Napier University had to obtain ethical permission from the School of Nursing, Midwifery and Social Care Ethical Committee. Studies involving NHS patients or employees were also required to have approval from COREC.

Ethical approval for this study was granted by COREC very swiftly, but subject to three conditions. The main stipulation was that participants had to be recruited through a gatekeeper (a person who controls access to participants). Disclosure by a participant of sexual abuse was another concern and the Committee required that if this situation arose it had to be the woman's decision to take the matter forward. The last issue was that if the woman could not give consent to participate the family and paid-carers were not permitted to be approached.

Once COREC approval had been received, an application to the Ethical Committee at the Social Work Department was made and after a telephone discussion about the research, permission was granted. Copies of the information and consent forms can be found in Appendix 6. These all complied with the Department of Health Guidance (DoH 2009) and British Psychological Society (BPS) guidelines (BPS 2006).

During the study, an amendment to the original COREC application was made to lower the age of eligibility within the project for women with LD. The request was to lower the age from 50 to 45 years because of poor recruitment. The rationale for setting the age at 45 was that these women would be the next cohort who would be screened. A copy of all the approval letters from COREC can be found in Appendix 7.

3.4.3. Consent in research

As stated in Chapter 1, it is presumed that an individual has capacity to give consent unless proved otherwise (Keywood, Fovargue and Flynn 1999). One difficulty identified with obtaining consent is that some participants, such as people with LD, do not understand that they can say 'no' (Dunn *et al.* 2006; Freedman 2001; Goldsmith, Skirton and Webb 2008). This is relevant for people with LD because they have additional problems, namely difficulty in processing and understanding information and this is compounded by their verbal and/or written comprehension problems (Clare and Gudjonsson 1993; Clements 1987; Goldsmith, Skirton and Webb 2008). Acquiescing (agreeing without objection) can also be problematic in research undertaken with people with LD, as Dye, Hare and Hendy (2007) reported. They found that people with LD were very willing to take part in their study despite the fact that they had been assessed as being unable to consent. This raised concerns about signing the consent form as people with LD could be signing something they did not understand (McCarthy 1998). Until recently, there had been little guidance about obtaining consent from people with LD but more is now appearing (BPS 2006; DOH 2009; Goldsmith, Skirton and Webb 2008; McLeod 1994; Medical Research Council 2007; Swain 1998).

To help people with LD understand the consent process, a number of factors have been identified. Cea and Fisher (2001) suggested that the type of information and how it was presented were important. Building up consent in stages has also been advocated as this has been found to enable people LD to feel more comfortable with the process (Green and Nicoll 2001; Milne and Bull 2001). Similarly, the use of 'concrete' facts has been found to be better understood than employing abstract concepts (Dye, Hare and Hendy 2007; Fisher *et al.* 2006). Other ways to help people with LD understand consent include reading vignettes (a descriptive summary) out loud to the participant, having previous experiences of taking consent, breaking down information into 'chunks' and using short, clear text and appropriately tailored language (Broughton 2002; Cea and Fisher 2003; Wong *et al.* 2000). However, merely providing additional information or reducing memory load is not sufficient alone to enable people with LD to understand consent (Dye, Hare and Hendy 2007).

In their review about obtaining informed consent from people with LD, Goldsmith, Skirton and Webb (2008) were cautious about recommending one approach although they suggested 'chunking' information, reducing the cognitive demands and tailoring it to the individual could improve capacity to give informed consent. They also acknowledged that general IQ, as well as verbal and memory capacity had an impact but pointed out that factors such as experience of decision-making were also relevant to the process. Similarly, Nind (2008) in her review cites the current state of knowledge rather than advocating one method.

3.4.4. The process of consent in this study

For the consent process I drew on the guidance within the literature and my previous experience. Consent was always undertaken in steps for participants with and without LD. In women with LD, I always met with them prior to asking for consent as I believed it was important to develop some rapport with the participants. This provided me with an opportunity to explain the study and to look at the information sheet with them. It also enabled them to ask questions. In four cases, the women brought a paid-carer to this meeting and this provided an opportunity for me to discuss the research and address any concerns or

questions they had. When I was talking with the women, I would break the information down and use the information leaflet, easy-read flyer and pictures which were part of the pictorial prompts used during interviews. Pippa, for example, read the easy-read flyer and asked 'Did her paid-carer have to be there'? When going through the information leaflet, I reminded the women they could ask questions if they wanted to. This was seen as good practice as very often people with LD are not used to being consulted or asked about their opinions (McCarthy 1998). I explained to the women that I wanted to know more about their experience of breast screening in order to help other women who have to undergo the procedure. As in previous studies, I explained about writing this up for publication (like a magazine), anonymity (no one would know who they were) and confidentiality (no one would know what we discussed).

The women were then given a week to think about taking part. I explained that they would be contacted by myself in a week to see if they wanted to participate. I also stressed that I was happy to be contacted during this week to discuss the study and that they could have more time if they wanted. I adopted this approach because I did not want to pressurise them and some may have wanted to discuss this with others, such as their paid-carers. During this meeting a provisional date for them to be observed or interviewed if they agreed to take part in the study was also set. Time has been identified as a difficult concept for people with LD to understand, although there is a dearth of research in this area (Owen and Wilson 2006). To help them understand, I used a number of different methods tailored to their needs such as a calendar, their timetable, or number of sleeps. None of the women rang me in between, although one paid-carer rang me to say her client was not well. If there were further questions, I would answer them and before I left I would give them a copy of the information sheet (I also left a copy for their paid-carer). If they agreed to take part when I next contacted them, I would return on the pre-arranged date where I obtained formal consent.

Prior to asking the woman whether she was happy to consent to taking part in the study, I would ask her simple questions such as whether she remembered me, and if she remembered anything about what we had spoken about previously. Typical replies are illustrated by Tanya who used my name and

said, 'you're asking me about my breasts'. Again when I spoke to the women I broke the information down and used pictorial prompts. I would also ask several times in different ways (verbally and pictorially) whether they wanted to take part in the study to ensure that they were not simply acquiescing to my wishes. With Vera, I showed her the pictorial prompt and then we chatted about her knitting before I asked her again if she wanted to be interviewed, reinforcing this again with the pictures. Wendy read the consent form to me and told me about the other studies she had participated in.

During this time I reminded the women about opting out at any stage of the research and it being 'okay' not to answer a question or not to be observed. I also reinforced that they could refuse (say no) without having to explain their reason to me. Three women declined to participate in the study and I believe this demonstrated good consent procedures. I also asked if they wanted to be taped or for me to take notes. I accepted written or verbal (taped) consent due to literacy problems as this ensured the women were not merely signing a form which they did not understand. Once consent had been given, I conducted either an interview or period of observation as agreed.

For the participants without LD, I again tried to meet with them before obtaining their consent and I was able to meet with all but nine of them. Reasons for not meeting with these participants were due to their lack of time or knowing them already. For the nine I did not meet (n= 4 allied-professionals, n= 3 paid-carers, n= 2 family-carers), I spoke to all of them on the telephone about the study and sent them the information sheets. Again the participants were given time to think about taking part and I agreed to contact them again in a week. This gave them time to think about taking part and if necessary to seek permission from their line manager. I stressed that I was happy to be contacted during this week to discuss the study further, that they could have more time if they wanted and that it was OK for them not to participate without any adverse effects. None of the participants contacted me prior to me re-establishing contact with them. When I met with the participants, I again explained the study, went through the information sheet and asked whether they preferred to be taped or for me to take notes.

3.4.5.   Reflexivity: Ethics

Ethical approval had been something I was concerned with, as it had taken eight months to obtain permission for my previous study. Rule changes meant this process was much smoother, but I was surprised and reassured when at the meeting for approval the Chair recognised me and spoke encouragingly to me about my research. This boosted my confidence that the proposal I had put forward was worthwhile. Reflecting on my approach to consent, my supervisors were surprised at the number who declined to be taped. If I had ever been in doubt that the women were not happy to take part or be taped I would never have proceeded to obtain their consent. Consenting the women was always something I was cautious about and in my notes I wondered if at times I had been overcautious. In retrospect, I believe my approach was ethically and professionally driven and in keeping with the importance of this procedure.

3.5. Part four: Sampling and recruitment

In qualitative studies, researchers are less concerned with identifying the total population of people, events or settings in order to develop a sample (representative section of people, settings or events). Rather, key events, individuals or settings are sought to provide data (Gerrish and Lacey 2006). However, the diversity of the informant's world needs to be reflected in the data collection (Hammersley and Atkinson 2007). There are two types of sampling: probability and non-probability. Parahoo (2006) described probability sampling as the basic presumption that every individual, setting or event has a known chance of being selected in contrast to non-probability sampling where the chances of being selected are unknown.

3.5.1. Sampling techniques

The sampling procedure most often used for qualitative research is non-probability sampling. This is because participants are selected from an accessible population where they have developed a relationship (Gerrish and Lacey 2006). Snowballing is one technique of non-probability sampling where human networks are employed to gather a sample or identify participants (Parahoo 2006). This was not used in this study because there were selection criteria that had to be adhered to. Furthermore, there were a number of different settings involved and it was important that the best participants possible were selected from each of these environments. For similar reasons, accidental sampling or convenience sampling, where the participants are chosen because they are in the right place at the right time were not used (Gerrish and Lacey 2006).

Purposive sampling is commonly used in qualitative studies and is defined by Bryman (2004) as a non-representative subset of some larger population, constructed to serve a very specific purpose. To do this, the researcher must map out the full range of settings and the people within them (Gerrish and Lacey 2006; Silverman 2000). Practical decisions then have to be made which are subject to two constraints: available resources and a lack of enough examples to fit each criterion. Purposive sampling limits the scope of

participants in terms of demographic range and size favouring quality over quantity but this is the purpose of naturalistic research (Parahoo 2006). Despite this, purposive sampling ensures that all participants are well-placed to provide data relevant to the research questions. Unlike positivistic sampling which searches for objective results, drawing evidence from randomly selected samples, naturalistic research pursues the complex subjective understanding which necessitates small selective samples.

3.5.2.   Gatekeepers

Many studies rely on gatekeepers and they are often used to recruit participants and settings but there are advantages and disadvantages in employing them (Bryman 2008). An advantage identified by Sampson and Thompson (2003) is that they give access to individuals within the setting. However, the individual identified may not always be the most willing or appropriate person within the setting. Approaching gatekeepers has been found to be useful when the researcher has not known the line of command or other local protocols in order to gain access to participants (Feldman, Bell and Berger 2003). The researcher must be mindful to the possibility that the gatekeeper may only allow access to certain participants and thereby influence data collection (De Walt and De Walt 2002; Sharkey and Aggergaard Larsen 2005). Moreover, gatekeepers can also block access as has been found in some work on people with LD (Stalker 1998; Tuffrey-Wijne, Bernal and Hollins 2005).

Using gatekeepers (such as paid-carers) to recruit people with LD has been seen as problematic, since their decisions are sometimes overturned by their paid-carer. This has been described as the 'we know best' attitude amongst those who support people with LD (Dines and Cribb 1993). Walsmley and Johnston (2003) noted in *Good Times, Bad Times* that one of the women, who had contributed a story to the book, asked her mother to look at her chapter. This resulted in the mother (along with her daughter) meeting one of the authors (Jan Walsmley) and making changes to the chapter. Walsmley wrote that she agreed only because 'her daughter was also at the meeting' and she noted a similar incident happening with the agency overseeing the work (Walsmley and Johnston 2003: 105).

The use of gatekeepers by researchers as a means of contacting participants for their research is common when they are not in contact with clients in the field they research. As already discussed this was also a requirement of my ethical approval for the study (see section 3.4.2.). The strategy I used was to contact individual gatekeepers in the area I wished to access to explain my study. For access to the NHS, day centres, residential homes and voluntary sectors, the managers were approached in the first instance. For social work, I used the research co-ordinator, while to gain access to GP practices I had to approach the Scottish Primary Care Research Network coordinator. I first approached the gatekeepers I already knew, i.e. the non-social work day centres and residential homes and community LD nurses, before I proceeded to those I did not know (social work, GP Practices) and discussed the study with them. This strategy was chosen because I was aware of the 'line of command' or other local protocols in the settings with which I was familiar which helped accelerate access to participants (Feldman, Bell and Berger 2003).

In the main, most gatekeepers were helpful, and most allowed me to access whomever I wished (Sampson and Thompson 2003). Only one day centre did not allow me to carry out my study (reasons for being denied access are discussed in section 3.5.4.). Three paid-cares also refused me permission to speak with three women with LD who had already consented to taking part and reflected the 'we know best' attitude as described by Dines and Cribb (1993). When this happened, the reasons for not using the women in the study were explained to them and they were thanked for their time. Other researchers who worked on other projects with people with LD had also experienced this and as a group we concluded that although the attitudes of the paid-carers should be explored, it could result in jeopardising future research. This was the reason for complying with the wishes of the paid-carers. In terms of concerns about the project and my role within it, the gatekeepers preferred to identify my position as that of a volunteer (this is discussed fully in section 3.3.2).

3.5.3.   Recruitment for this study

This study used purposive sampling. To ensure that the settings and participants were representative, a list of the different types of people and

places was drawn up. This was based on my previous knowledge about the area. Women with LD were chosen because they were the focus of the study, however I knew that I would only be able to recruit women with mild to moderate LD because those with severe and profound LD would not have capacity to make an informed decision (this was also a stipulation of my ethical approval). My experience of health-related work with women with LD highlighted the need to include people who supported the women with LD, including allied-professionals[3] (from health, education and social care), paid-carers who were residential or day-centre carers, working within the NHS, voluntary or social work sectors, and family-carers. All participants were subject to an inclusion criteria for age:

- Allied-professionals, paid or family-carers as follows: 16 years or over

- Women with LD 45 years of age or over

There were other criteria for the women:

- Have enough speech to be able to be interviewed

- Mild-moderate range of LD (confirmed with each gatekeeper i.e. carer or allied-professional)

- Have capacity (i.e. make their own decisions)

My knowledge of the area enabled me to identify the settings that the participants would access or work in as well as involving those from the Breast Screening Centre (BSC). Table 5 shows the number of areas approached and those that participated or declined to be involved in the study.

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[3] Allied-professionals were drawn from health, education and social care. They are called 'allied-professionals' because when contacting participants from social care and education they clarified that they were not health professionals but allied-professionals. This term was therefore adopted.

Table 5   The number of areas approached for recruiting potential participants

Setting	Number approached	Number agreeing to participate	Reason for not participating
Day centres	7	4	2 did not reply to invitations to participate despite follow ups over 10 and 6 month periods respectively. 1 refused access.
Residential settings	9	6	1 was participating in another study. 1 had just re-organised and was in a state of flux. 1 had no eligible women.
Voluntary sector	2	1	Did not have anyone supporting clients with LD.
NHS Premises	7	7	-
GP Practices	5	4	1 practice withdraw agreement due to staff shortage
Total	30	22	-

3.5.4.   Recruiting participants

The recruitment process was undertaken in stages. Initially I contacted the gatekeepers (mangers of day centres, residential settings, voluntary organisations and community LD nurses and other health professionals) in the settings that I had already built up a rapport with before I proceeded to those I did not know (social work, GP practices). The initial contact was undertaken to discuss the project and gauge interest. I also provided the gatekeepers with details of the study and went through the information sheet and recruitment

criteria with them. If the manager agreed, recruitment would commence. However, the ways in which each gatekeeper managed the recruitment process differed.

In two areas I had to obtain permission from managers, paid and family-carers prior to approaching the women with LD about the study. In another two other areas I was allowed to approach the women with LD first and then, if she consented to take part, I had to get the permission from her family or paid-carer before formally interviewing or observing her. This meant that there was the potential for a gatekeeper to refuse access to an informant and in three cases the gatekeepers over-ruled the woman's decision to participate. Discussions with other colleagues in the field suggested that it is always better to keep 'good relationships' with organisations and my decision in these circumstances was to thank the woman and explain the reasons for not pursuing her as an informant.

In one day centre, I was denied access having previously been given access. This was because one of the paid-carers objected to my information leaflets because she thought it inappropriate to give out material containing the word 'breast'. She believed that male clients who overheard the conversations about a project involving breasts 'would get excited.' Despite her concerns, she wanted to champion the project at the staff meeting. Unfortunately, at this meeting the rest of the staff decided that the project was not relevant as 'health was not their remit.' They also refused to give out the leaflets to the women to show them to their paid or family-carers.

Volunteers and family-carers proved to be the most difficult group of participants to recruit. Reasons given by family-carers were that they believed they had nothing to offer. Although I contacted a carers group who agreed to write to carers looking after family members with LD (see Appendix 5 for the letter of approach) only of 10% (3/30) responded to the request. However, low response rates to postal requests were commonly referred to in the literature (Sapsford 2001). Volunteers were also difficult to recruit. Despite asking within the voluntary sector and established independent sector organisations, there were few people volunteering with this client group at the time of the study.

Accessing the Brest Screening Centre (BSC) was also difficult, despite having worked there as a nurse and a data manager. Gaining access took several telephone calls and email exchanges with the manager who knew me well and welcomed the study. However, it took five months to get the BSC manager to confirm dates for me to come in. This was probably because there had been a number of changes in staff. Although I had originally planned to spend three days there, I was only allowed access for one day. The reason given was the demands by medical, radiography and nursing students wanting placements and this was considered a higher priority.

The true number of potential participants approached was unknown due to gatekeepers operating at different levels of confidentiality. Some disclosed the number of potential participants they had approached whilst others did not. Table 6 below indicates the number of potential participants known to have been approached, the number recruited (including those who took part in the pilot study) and those who declined to participate.

Table 6   The number of potential participants approached, recruited and those who declined to participate

	Women with LD	Paid-carers	Family-carers	Allied-pro-fessionals	Total
Approached	24	14	32	17	87
Recruited	14*	12	3	13	42
Pilot	2	2	0	3	7
Main study	12	10	3	10	35
Declined	10	2	29	4	45

*(n = 5 mild LD, n = 9 moderate LD)

There had been 45 potential participants who had declined to take part in the study. Apart from those women whose paid-carers refused their permission, three women with LD declined and gave no reason, one woman wanted her paid-carer to support her but was unable to schedule time to support the woman. Two women were unable to take part because they had a recurrence

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of illness and mental health problems, while one woman's mother died. Of the allied-professionals that refused, one had only just started her post, while three GPs declined because of illness and 'pressure of work' and could not recommend anyone else in their practice. Of the paid-carers, one was off work due to illness for the duration of the fieldwork period and the other did not want to compromise the decision of the workplace not to participate (see above). Of the 30 family-carers who were contacted by post, 27 did not respond. Of the three who responded, one said they did not want to participate, one was going to participate but was then diagnosed with a serious illness, leaving one who participated.

Of the 35 participants who took part, only two were male (an allied-professional and a paid-carer). This reflected the nature of the care sectors which are predominantly staffed by females. The allied-professionals worked with people with all levels of LD, whilst the family-carers supported women with mild to moderate LD. The paid-carers varied: three supported women at all levels of LD and four supported women of mild to moderate LD while three supported women with severe to profound LD. The ages of the participants can be found in Table 7 (below); other details about the participants are given in Chapters 4, 5 and 6.

All 35 participants recruited for the main study consented to be interviewed, however only nine participants (women with LD n = 3, paid-carers n = 2, allied-practitioners n = 4) agreed to be observed. The reasons for the limited observation were that participants declined to be observed and either gave no reason (women with LD n= 9, paid-carer n= 1 and allied-professionals n=2), worked with people with LD who were unable to give consent (paid-carers n=7, allied-professionals n=4) or said they would not be involved in any health related activity (family-carers n=3). It was notable that permission to observe paid-carers and allied-professionals who worked with people with severe to profound LD was problematic and resulted in permission being declined because their clients were unable to give their consent. In another area, permission was declined because some of the women were unable to distinguish between a new member of staff and someone like myself who only visited once or twice.

Table 7   Age bands of the participants

Age of participants	Number of participants			
	Women with LD	Allied-professionals	Family-carers	Paid-carers
40-49	2	-	-	-
50-59	6	-	-	-
60-69	4	-	-	-
21-25	-	1	-	-
26-30	-	-	-	1
36-40	-	3	-	2
41-45	-	2	1	3
46-50	-	2	1	1
51-55	-	2	-	2
56-60	-	-	-	1
60-65	-	-	1	-
Total	12	10	3	10

3.5.5.   Reflexivity on recruitment

The greatest challenge within the recruitment process was the difficulty of getting past the gatekeepers. My frustrations with paid-carers, especially with those I believed were obstructing the women from having autonomy in participation, were vented in my field-notes. I had similar frustrations when I was turned away from the day centre because the paid-carers believed health was not their remit. Within my field-notes I was able to work through my frustrations and understood that these paid-carers believed that they were acting in the best interests of the women. The challenge I had was to remain professional and accept that their justifications for this were equally as valid as mine in the pursuit of the study.

3.6.   Part Five: Data analysis

In the preceding section, discussion focused on how the sample was identified, permissions obtained and the research tools used. In this section the focus is on the process of data analysis. It begins with discussion of the choice of framework for the analysis. This is followed by a rationale for the framework selected and how it was used. Finally how the findings were brought together for the discussion in Chapter 7 is documented before exploring the trustworthiness of the findings.

Data analysis can be defined as a process in which raw data is organised and ordered so that 'sense can be made of the chaos' (Gerrish and Lacey 2006:415). This is not always a linear process. Qualitative data analysis should be seen as a process that involves producing 'findings' rather than results because the researcher is part of the process (Barbour 2008; Parahoo 2006). For this reason the researcher has to be mindful of their preconceptions and interpretations of the participants' world prior to and during the analysis to ensure that this does not impact on their understanding of that world. The researcher should think critically about their data and the conclusions which may be drawn from it (Mason 2002). Careful consideration should therefore be given to undertaking data analysis.

3.6.1.   Choosing a framework of analysis

In ethnographic research the analysis of data is the process by which data is funnelled because data analysis is seen as an on-going process and not a distinct stage of the research. Thus analysis begins in the planning of the fieldwork and continues through formulation of the research problem until the final report writing (Hammersley and Atkinson 2008). The breadth of phenomena studied by ethnographers also accounts for the variation of data presented, from the descriptive to typologies or models of social processes. Unlike Phenomenology or Grounded Theory which have specific frameworks of data analysis such as those developed by Giorgi (1985) or Colaizzi (1978) or Strauss and Corbin (1998), Hammersley and Atkinson (2007) have re-emphasised that there are no set formulae for analysis of ethnographic data.

They do, however, allude to a number of general principles to data analysis which are similar to those proposed for qualitative work in general textbooks on this subject (Barbour 2008; Flick 2009; Mason 2002; Parahoo 2006). These principles are summarised below:

- 'Getting to know the data' by reading and re-reading what has been collected.

- Through this process the researcher can break down the data into categories or codes.

- Group these codes or categories together under themes based on similarities.

- Draw the themes together in an order to describe the phenomena under study.

Barbour (2008) has also suggested that researchers should treat the reading of relevant literature and theory as the same as a framework for analysis since this can identify discrepancies, gaps and contradictions. Ethnographic work should not start from a well-defined theory as the researcher's prejudgements could force data in to a certain mould. Rather, any theory should be used as a resource to make sense of the data (Hammersley and Atkinson 2007). Hence it is not unusual to draw on different elements of theory to understand data (Barbour 2008; Hammersley and Atkinson 2007).

3.6.2. The chosen approach to data analysis

The aims of the analysis were to draw together the experiences of the participants I had interviewed, observed and written about in my field-notes and through the analysis explain what factors influenced women with LD to participate in breast screening. Within the thesis I have used reflexivity to address any preconceptions and highlight areas where the trustworthiness of the findings might have been compromised and explained how this was resolved.

My initial approach to the analysis was to search the literature to establish what had been written on analysing data combining views of people with and without LD. This proved fruitless. Indeed the most recent papers from the Northern Ireland team separated their data into carers, women with LD and practitioners (McIlfatrick, Taggart, and Truesdale-Kennedy 2011; Taggart, Truesdale-Kennedy and McIlfatrick 2011; Truesdale-Kennedy, Taggart and McIlfatrick 2011). With most of the literature there was little detail about how data were analysed, with the exception of McCarthy (1999) who described a four staged process called the 'editing style' (see below). This had been used previously in research that sought to explore and generate knowledge where little already existed and to give a voice on issues rarely discussed in people with LD (Miller and Crabtree 1992).

'The editing style' of McCarthy (1999) consisted of the following:

1. Read and re-reading the transcripts.

2. Summarise the transcripts and draw out key points.

3. Categorise these responses. Using the categories return to your data and interpret what the participants said using their words to explain the overall picture.

4. Examine basic themes, patterns of shared experience and diversity.

This framework was similar to that of Smith (1999) and Smith and Osborn (2003) detailed below:

1. Read the transcripts and note in the margin anything that strikes the reader or is significant about the respondent.

2. On the other side of the margin document emerging themes using key words to capture what you are essentially finding in the text.

3. List the themes and look for connections.

4. Produce a master list of themes which capture the respondents concerns on this particular topic. Within the master list, sub-themes may also be identified.

5. Locate what was said and where, then map the themes and where they came from. Some of the themes will be governed by and follow closely questions on your schedule, but others will be completely new.

Given the problem of a lack of analyses which combined women with LD and non LD, I decided after discussions with my supervisors to combine the two frameworks (see below) and adapt this to a framework which also synthesised the steps in the generic textbooks. The reason for combining them was to develop a framework adapted from the perspectives of a LD study and one derived from the general population. I had originally presented my data to my supervisors in the format of the women's views combined with those of the allied-professionals, paid and family-carers views. However, having taken some leave due to a number of bereavements and gaining a new post as a lecturer, my decisions changed.

While discussing my work with two colleagues (who became my critical friends), they dissuaded me from combining the views of the supporters as I had attempted. I abandoned this analysis and instead presented the views of the women, the carers (combining the paid and family-carers due to there only being three family-carers) and allied-professionals separately. Within the same discussion, we spoke about how the findings might be written up. Once all the views were written up and finalised, a cross-analysis was undertaken to help

structure the discussion and synthesise the data. For this reason I adapted the framework to include a fifth step, that of cross-analysis: comparing the themes from the views across and within the three groups to synthesise the data further.

My analysis framework now consisted of the following steps:

1. Read and re-reading the transcripts.

2. Begin to document emerging themes using key words to capture and summarise the data.

3. List the themes and look for connections, using their words to explain the overall picture.

4. Produce a master list of themes which capture the respondents concerns, shared experience and diversity on this particular topic.

5. Cross analysis – synthesise the themes from all groups to provide an overall picture.

In undertaking my analysis I chose not to use the QSR Nivo® software package because I had used it before with a much larger dataset. Although I found it useful to 'manage' data, it was cumbersome to use because I needed to write down the decisions I had made about nodes and node trees in order to keep track of what I had done. I also needed remember to re-label the nodes as I often lost the previous data I was working on because it automatically overwrote my data. Since the dataset was smaller in this study, it was feasible to employ more traditional methods such as coloured pens, post-it notes and my word processor to highlight and capture themes. Using this method I was able to highlight certain words on the transcripts and on the word processor such as 'sore', 'painful', 'hurt', when the informants spoke about 'having' breast screening. I could also feel and touch the transcripts and data which made it more visual and I was better able to keep track of my decision-making process. How the steps in the framework were conducted will be discussed below.

3.6.3.   Reading the transcripts through

The first stage of the analysis involved familiarising myself with the transcripts.[4] I read through these and also listened to the recorded interviews to become fully acquainted with them. The interview transcripts and recordings were all read and listened to at least eight times, as were the field-notes and observation schedules. Smith (1999) and Smith and Osborn (2003) suggested that whilst reading the transcripts the researcher should also note anything that strikes them as significant. During this process, any thoughts, feelings or ideas were written in the margin of the document. When I had finished reading or listening I also transcribed my comments and thoughts into a Word document. As the transcripts were already in a Microsoft Word document I created a table and put the transcript in one column of the table and transcribed my thoughts into the adjacent column. An example of this is presented in Figure 1.

Figure 1   Extract from transcript and emerging thoughts from a paid-carer

Interview: Margaret (paid-carer)	Thoughts
".... Erm I know there still **are odd clubs** and odd groups still going on and I think they seem to be doing that kind of work at the **higher end of need**. Where communication is certainly **more difficult** I **don't think there is any opportunity** to try and **tell someone how you feel** and I certainly **not aware** of anything like that. I think the breakup of 'institution' situation meant that **some people are more isolated**......"	Odd clubs – nothing readily available? People more isolated since 'Care in community.' Few outlets for people with LD to get together – more for those who can communicate – not so for those who have less language. Isolation.... friends poor...

3.6.4.   Documenting emerging themes

The next stage was to document emerging themes, using key words to capture the essence of what was being said. During this process I also summarised the

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[4] This denoted the interview transcript, observation schedule and field-note data

transcripts (known as memos). Payne (2007) has suggested that memos are useful for capturing the thought process especially as they could be returned to, to compare preliminary ideas and thinking. McCarthy (1999) also found it useful to highlight relevant issues. I found that using memos helped me to review my data. This also helped to bring the different types of data together. An example of the process is shown in Figure 2.

In Figure 2, Clary, Ronnie and Jo (allied-professionals) are all talking about or discussing breast awareness with the women. They are mindful about acquiescing, checking the women's knowledge and reminding them about breast awareness. They are also aware of their boundaries and all showed respect to the women. Talking about this subject was potentially difficult and this was captured in the theme discussing breast health.

3.6.5.   Listing themes and looking for connections

The next stage was to list the themes and look for connections. Smith (1999) and Smith and Osborn (2003) suggest that themes should be collated and the researcher should look across and within their emerging themes. This helped to shape the master list. I listed all the themes for each group of participants from all the different data sources and began to sift through the list looking for connections. I referred back to the original data to ensure that the essence of what was being said was summarised within the theme. An example of how I sorted my themes and looked for these connections is exemplified in Figure 3.

Figure 3 shows extracts from the different data sources for three women with LD who were participants. The emerging themes from the different sources are listed and connections made to inform the final themes.

Figure 2   An example of emerging themes and summary of an interview transcript, observation and field-notes from the allied-professionals

Interview: Clary (allied-professional)	Thoughts	Summary and potential theme
*"Well no every time, so every 6 months or so I will **say are you having a wee check** like and she **claims she does**. But the difficulty being, **a lot of our clients can say what you know you want to hear** but **whether they are carrying** it out that is where the **difficulty lies".***	Checking/awareness about breast. Belief about claims – says what you want to hear. Difficulty checking claims. Problems of discussing breast awareness. Boundaries. Role/duty of the AHP.	The AHP's beliefs knowledge about the client group suggests answers need to be checked out. A hidden meaning perhaps about their duty to care and the many boundaries.- dignity, professional, not pushing something **Possible themes/subthemes** Acquiescing – culture/part of LD Problems of discussing breast awareness and ensuring it is followed through Duty to care - boundaries Knowing this client group
Observation: Ronnie (allied-professional) and Pippa (woman with LD)	Thoughts	Summary and potential theme
*"...Ronnie asked Pippa: Can you remember what we said about **checking your breasts last time**? Pippa was hesitant but said she could. There was silence. Ronnie asked her '**what do you check them for**' there was a pause, 'you check **them for lumps'**. Ronnie **praised** her..."*	Checking/reminding - supportive questioning. Breast awareness. Lumps. Praise.	Ronnie reminded Pippa about checking her breasts. This tested Pippa's knowledge. Knew to check for lumps. Reassurance/praise given. **Possible themes/subthemes** *Lumps.* *Checking knowledge/culture part of LD* *Reminding about breast awareness discussing breast health.* *support – praise.*
Field-notes Jo (allied-professional)	Thoughts	Summary and potential theme
"Being a SALT – there was emphasis placed on discussing subjects such as breast screening – difficult to broach the subject.... need to know client and have good rapport. ...'often need to remind the client'....depends on LD 'can't force them only advise'".	Supportive relationship. Reminds client- knows boundaries. Broaching health.	Discussing breast screening can be difficult dependent on LD of client. Need to have good rapport respect the client and their boundaries. **Possible themes/subthemes** *Talking about breast awareness.* *Boundaries.* *Respecting client.*

Belief about claims/What you want to hear.
?duty to care.
Boundaries.
Difficulties checking up- need to check.
Support.
?Theme: discussing breast health.

Health problems.
Knowledge.
Support.
Reminding about breast health.
Discussing breast health.
?Theme: discussing breast health.

Respecting client.
Boundaries.
Discussing breast awareness.
?Theme: discussing breast health.

Figure 3   An example of looking for connections within the emerging themes from sections of data from women with LD

Interview: Jane	Observation: Wendy	Field-notes: Pippa
Letter	**I had letters**	Checking for lumps
A big X-ray machine	**Nurses has explains things**	**Nurses explains things**
It's not painful	**I don't want to go**	to make sure they are ok
Reassurance	**Painful**	**It was painful**
Being nervous	**Bad experience**	**Nurses explains things**
You were in and out.	You can put me down before I go	**I didn't like it**
Staff explain things	**Have a look round**	**I felt exposed**
I go for a treat		**I had a picture taken**
I can say no		**Lunching out was good.**
Telling staff if there were problems.		Staff support me
		I can say no
		I don't want to be ill again
		Staff explain things
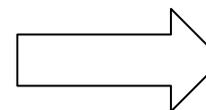
Going for breast screening:
Letter
It's not painful vs It was painful
Being nervous - I didn't like it
You were in and out
I felt exposed
I had a picture taken - A big X-ray machine

Being persuaded to go to breast screening:
Staff explain things vs Nurses explains things
I won't go
Previous experience
Have a look round

Eating for health:
Lunching out was good- I go for a treat

3.6.6.   Producing a master list of themes

The final stage recommended by McCarthy (1999), Smith (1999) and Smith and Osborn (2003) was to produce a master list of themes which captured the respondents' views on the topic under study. Barbour (2008) suggested that in order to produce the final themes the researcher has to be ruthless and whittle away the many themes they have created. I was also mindful that McCarthy (1999) advocated the final themes should not only reflect the shared experience but also the diversity. Figure 3 demonstrated this with Jane suggesting that breast screening was not painful in contrast to Pippa who said it was painful. Through this process the final themes and sub-themes that emerged for all groups are listed below in Tables 8 to 10.

Table 8   Themes and sub-themes representing the views of the women with LD

Theme	Me and my health	Breast screening
Subtheme	Keeping myself healthy Eating for health Checking for lumps Experience of breast problems	Being persuaded to go Going for breast screening I won't go back

Table 9   Themes and sub-themes representing the views of the carers

Theme	Doing the best we can	A few more difficulties
Subtheme	Care within boundaries Keeping an eye on things Food and health	Trying to explain breast screening It's their choice The problem is...

Table 10   Themes and sub-themes representing the views of the allied-professionals

Theme	Talking about breast health	Perceptions of others
Subtheme	Discussing breast awareness Discussing breast screening Barriers to breast screening	Breaking down the barriers Carers

3.6.7.   Cross-Analysis

In order to present the findings for the discussion in Chapter 7, my critical friends suggested that I undertake a cross-analysis: looking between and within the respective findings would help to synthesise the conclusions and give a manageable overview of the views from the three groups. This would produce a means of organising the discussion.

To do this, I first wrote up the findings of the women, carers and allied-professionals. This helped me to understand the findings and made it easier to discern similarities and differences. It also focused my thinking on what were the key aspects of the findings. How I undertook this was to repeat the stage in the framework where I listed the themes and looked for connections (Smith 1999; Smith and Osborn 2003). A representation of how this was undertaken is found in Figure 4 which identified barriers to breast screening.

What I did was to read through the findings four times and then I began to map the findings across and within each group. In Figure 4 the women (box 1), carers (box 2) and allied-professionals (box 3) spoke about what prevented women with LD from attending breast screening. Figure 4 depicts how the findings were used to bring together the similarities and differences about what prevented the women from attending together by the arrows coming from the

text and going into a box entitled 'cross analysis: preventing going to breast screening'.

This process produced a list of themes from each group of participants and I began to sift through the list looking for connections. I referred back to the findings to ensure that the essence of what was being said was summarised within the theme. It also assured the trustworthiness of the findings. From this I would then formulate a theme which in this case was *'barriers to breast screening'*. This process helped to further synthesise the findings and draw out the main themes which could be used to organise the findings. I drew the overall finings together under the theme: *'Negotiating breast screening within the current service provision for women with LD'.* I then identified three sub-themes with which to organise the data: '*Cultural perspectives, 'Getting them through the door'* and *'Having a breast screening test'.* A fuller explanation of the findings of the cross-analysis is elaborated in Chapter 7.

Figure 4   An example of how the cross analysis was undertaken: to form the theme 'Barriers to breast screening.

1. Examples of women's findings: *"No I wouldn't go back...<u>It was painful.</u>"* (Helen, interview, page3) *"It's a bit <u>painful</u> to put your arm up and <u>stretched over</u>. It's not for very long. I don't like having it done very much. I have to because it's important I don't want cancer."* (Tayna, interview, page3)	**Cross-analysis: themes from each group** Painful Stretch over
2. Examples of carer's findings: *"<u>Sedation</u> might be a potential barrier? Maureen mentioned <u>sedation</u> for women who needed dental treatment. So did Veronica with Shelly who'd always been <u>sedated</u> for her cervical smear...."* (Sandra and Maureen, field-notes, page2) *"I think the main barrier is <u>fear of the unknown really."</u>* (Nicki, interview, page2)	Fear Sedation
3. Examples of allied-professional's findings: *"There is often the <u>fear factor </u>as some of our clients have <u>experienced lots of appointments</u> for lots of different things and lots of them <u>may not have been pleasant</u>."* (Jo, interview, page2) *"Carol apologised to Julia for the wait, and explained that there had been a problem with the last lady. She showed us into the room and told Julia to take her blouse off, (Julia had undone it and was being <u>rushed to the machine, her breasts were exposed</u> and her blouse open this seemed undignified)........"* (Observation1, Carol, page2)	Unpleasant appointments Being expose/dignity

3.6.8. Trustworthiness

There is a tradition in qualitative work for the researcher to demonstrate to themselves and others that their findings are representative of the phenomenon under study (Morse and Field 1996). Ensuring integrity within qualitative research has presented problems because the events that are captured are momentary and each researcher has a different rapport with the area and subjects within it. Hence the 'truth' cannot always be replicated (Morse and Field 2002). This does not exonerate the researcher from offering evidence for the claims made (Hammersley 1992). A number of means for demonstrating trustworthiness of findings have been advanced, ranging from undertaking quantitative research to test out the credibility of the findings, peer review, triangulation and taking the findings back to the people in the study (Appleton 1995; Cavanagh 1997; Cutcliffe and McKenna 1998; Denzin 1970; Guba and Lincoln 1989; Hammersley 1992; Leinenger 1992; Nolan and Behi 1995).

One means to ensure trustworthiness employed by ethnographers is triangulation. This refers to the checking of inferences drawn from one set of data sources by collecting data from others (Bryman 2008). The most common form is method triangulation which refers to the use of more than one data collection technique (Hammersley and Aitkinson 2007). Interpretations of concepts can be checked by examining data relating to that concept from different sources and seeing if they tally. Where data does not correspond, this may be due to 'random error' or because the collection methods used and merged were incompatible: for example, different questions may have been posed within each data collection method (Perlesz and Lindsey 2003; Wallace 2005). Where data does tally, Hammersley and Aitkinson (2007) warn that it does not necessarily mean that the inferences involved were correct. Triangulation has been further criticised as a form of validation on two accounts. First, because it assumes that each data source has caught an accurate picture of reality, rather than one among many possible versions of social life (Silverman 2000). Second, that triangulation assumes that sets of data deriving from different research methods can be unambiguously compared and regarded

as equivalent in terms of their capacity to address a research question (Denzin 1970).

Another way data may be considered trustworthy is if they are deemed to accurately represent the features of the phenomena that they were intending to describe, explain or theorise (Hammersley 1992). Guba and Lincoln (1989) drew on the premise that the findings are credible when others from the culture recognised these experiences. Qualitative researchers such as Colaizzi (1978) have suggested that the findings should be shared with the participants because this helps to ensure the trustworthiness of the study, especially if it claims to represent their experiences and understanding. A criticism of this is that most informants would have only contributed to a portion of the findings. Therefore they may not recognise the overall conclusions and may want to change them accordingly (Cutcliffe and McKenna 1998; Silverman 2000; Walker 2005).

3.6.9.   Trustworthiness in this study

In this study, I used a number of different mechanisms to ensure my data was trustworthy. Reflexivity was one method which I have discussed within the previous section. In addition, I compared and contrasted the observations, interviews and field-notes throughout the analysis. This was undertaken again with the cross-analysis to identify the similarities and differences (tallies and non-tallies). I believed this was a hybrid of 'triangulation', where I compared different data sources with each other. One example of a tally was demonstrated with the women's experience of pain when undergoing mammography, as this was documented in the interview, observation and reflected upon in my field-notes. A non-tally was the mammographer who told me they needed paid-carers' help when performing a mammogram on a woman with LD, but her observed behaviour was different.

Peer review was also another means by which I 'tested out' my findings and I deployed this in a number of different ways. A method commonly used is getting other researchers to check the work (Hammersley and Aitkinson 2007;

Weber 1990). In this study I used my supervision sessions for this purpose. When I was beginning coding, looking for emerging themes, key words and summaries, I sent four extracts of transcripts to my supervisors. This was useful as researchers from different backgrounds or professions can often produce different interpretations of the same topic (Agar 1986) although Young and Chesson (2008) advocate that having knowledge of an area is important in qualitative analysis.

None of the supervisors had a background in LD but despite this they were able to verify my coding. I also presented the findings to my supervisors which allowed 'debate' within the supervision session and prompted me to defend my interpretations. One example was when it was suggested that I take out the women's experiences of pain and fear as these were possibly common to all women. I defended my justification for retaining this by relating it to the literature and lack of published work from the women themselves. I also presented preliminary findings at a conference and had the privilege of presenting with experts in the field such as Daniel Satgé and Reneé Proulx. Here I found that my findings were not dissimilar to the findings of Proulx (2008).

I chose not to give the findings to the informants for a number of reasons. Many people with LD cannot read, have problems with cognitive capacity and may not remember what they said. This, however, has been seen by one commentator as not allowing the participant the power of redress (Nind 2008). Instead, my findings were shared through a short presentation with three day centres and one Community LD team that had taken part in the study and had requested feedback. The findings were received with interest and any disagreements were not openly voiced, despite offering the opportunity to email, telephone or speak privately with me. Feedback from one of the day centres, from informants who had not taken part in the study, commented that the theme, *'I won't go back'*, captured their experience of breast screening. Those that did not take part in the study also commented that poor treatment put them off going for hospital appointments. The carers also recognised the problems of

trying to explain things to people with LD and the differences between the disability of the women and the divisions within their roles.

Using the views of my supervisors, peers, colleagues and the participants and others, as well reflexivity, I believe that the findings are representative of the people observed and interviewed.

3.7.   Chapter summary

In this chapter, I have discussed the rationale for the choice of approach (ethnography) and study design (observation, interviews and field-notes). I chose to present the theory behind each design before demonstrating how this was applied. I have shown how the study was guided by the principles of participatory research and how I managed my data ensuring trustworthiness through discussion and documenting my feelings in the sections of reflexivity. Data was analysed by use of an adapted version of Smith (1999) and Smith and Osborn's (2003) framework and incorporated the views of the women, allied-professionals, and paid and family carers. The views of all three groups are reported in the succeeding chapters. The chapter discussed ethical principles and how the sample was obtained. It concluded by alerting the reader to how the findings were synthesised to help me organise, present and discuss the findings in the final chapter.

Chapter 4: Findings: Women with Learning Disability

4.1. Introduction

In this chapter, the findings arising from the analysis of data provided by the women with LD are presented. Data is drawn from the observations, interviews and the field-notes. Pseudonyms have been used throughout this section to conceal the identity of the participants and places.

To recap, 12 women with LD participated in this study. The majority of the women reported living in group housing with either one or up to 10 other people. Four women lived alone in their own flat or house, whilst Honey was the only participant who lived with her family at home. None of the women had paid work, although most, with the exception of Pippa and Irene, had day-time activities. The activities of the other 10 women ranged from attending college courses or day centres, doing voluntary work or a combination of these. None of the women were married, although two of the women had boyfriends. All the women maintained a link with their own family. Irene was the only woman to have had a child, although Wendy had undergone a termination.

Two themes emerged from the analysis of data. The first theme, *'My health'*, explored how the women kept themselves and their breasts healthy and comprised of four sub-themes: *'Keeping healthy'*, *'Eating for health', 'Checking for lumps' and 'Experience of breast problems'.* These sub-themes reflected the questions from the early part of the interview about how they kept themselves healthy and were supported by evidence from the observation and field-notes. The second theme, *'Breast screening',* explored the women's experience of participating in breast screening. The sub-themes that emerged were '*Being persuaded to go', 'Going for breast screening' and 'I won't go back*'. These sub-themes reflected questions from the later part of the interview which explored their experience of going for breast screening and making choices. Again, the theme was supported by evidence from the observations and field-notes.

4.2.   My health

This theme explored how the women kept themselves healthy. The sub-theme *'Keeping myself healthy'* explored how the women maintained their health and kept their breasts healthy with the exception of eating healthily. Eating healthily formed the next sub-theme '*Eating for health'* because within the interviews, observation and field-notes, food was seen as an important part of the culture for these women. The sub-theme '*Checking for lumps'* explored the women's knowledge about how to check their breasts whilst the final sub-theme, *'Breast problems'*, focused on the women who had experienced breast cancer.

4.2.1.   Keeping myself healthy

This sub-theme reflected the interview topic exploring how the women kept themselves healthy and can be seen as a pre-determined theme because it reflected the interview topic. This topic was important in understanding the risk factors to breast cancer but caused the most problems for the women in that five women needed prompting to help them open up the discussion. The prompts used (drinking alcohol, smoking and exercise), reflected the identified risks factors in breast cancer: consumption of alcohol, smoking and lack of exercise. The remaining seven women spontaneously answered the question without needing to be prompted.

All of the women received some form of support to keep healthy, either with personal hygiene, cooking or finding activities. Six women were in regular contact with the nurse or hospital because of ongoing issues such as mental health, breast cancer, gynaecological or weight problems. One example was Wendy. She was prone to depression and other health problems such as passing urine so had a catheter. Clary, her Community Learning Disability Nurse (CLDN), was monitoring her moods and made regular visits.

> *"Did you make that appointment then? Clary had asked Wendy last week to get an appointment with her GP but she hadn't made it. Clary suggested she made it now. Wendy reluctantly rang the GP whilst complaining that 'antibiotics didn't work.'"*
> *(Wendy, Observation1, page1)*

When answering the question posed about how they kept themselves healthy, most women spoke about their diet and this is discussed in the next section. However, two women who answered the question spontaneously used their current health problems as a reference point to explain their lack of motivation in keeping healthy. They believed that it was more difficult to be motivated about your health when you had long-term conditions such as arthritis or mental health difficulties.

> *"Keeping healthy, it's how you feel, I have arthritis in my arm and my health is poor so I can't be bothered sometimes."* (Morag, interview, page2)

> *"Not always that great. My health has gone right down really."* (Wendy, interview, page1)

This was significant since it identified a reason why some women might not pursue health interventions such as breast screening. Despite both women living independently, when their health problems were acute they became more dependent on their paid-carers for help with personal hygiene.

Other aspects of keeping healthy, such as the consumption of alcohol, smoking and exercise were also discussed. None of the women held strong views on these. None of the women exceeded the recommended limits and half of the women said they didn't drink alcohol, while the other half said that they only drank alcohol on special occasions such as birthdays or Christmas.

> *"I have a wee drop of wine sometimes."* (Mairi, interview, page1)

Whether their limited alcohol consumption was their personal choice was not pursued in the interview because the focus was on the women's experience of

breast screening. Pippa, however, gave a reason for not drinking alcohol; this was because she was prescribed tablets to control her epilepsy:

> *"I am not allowed, because of my tablets."* (Pippa, interview, page1)

When asked whether or not they smoked, only two women in the study said they did. Tanya smoked the occasional cigarette, whilst Irene was trying to stop smoking because she wanted reconstructive surgery after her mastectomy. Irene's surgeon would not allow her to have surgery until she gave up smoking and she was finding it hard despite the support from her family, friends and paid-carers.

> *"I have cut back I am finding it hard. So I am trying to stop along with Bill and Hayley."* (Irene, interview, page2)

Again, reasons for why the other women didn't smoke were not pursued in the interview, although one woman Jane suggested that she might set the house on fire if she did. Although this reply might seem to suggest the woman having an awareness of the risks of smoking, it may also have reflected the views of the paid-carers.

When asked about what exercise they did, this was clearly related to the influence of the paid-carers. The most popular form of exercise was walking, although other activities were also mentioned.

> *"I go for a walk up the street."* (Helen, interview, page1)

> *"I like bowling and walking."* (Rona, interview, page1)

> *"I got [the] gym. I go 2 days a week with my centre."* (Honey, interview, page1)

Some women had additional exercise activities in place. Jane lived alone and her care organisation had organised a 'befriender' (someone who volunteers to do activities with a person with LD) who took Jane swimming. In contrast, Mairi lived in a group house with two others and had access to an exercise bike which she kept in her bedroom. Mairi had asked staff to help her buy an exercise bike and they fully supported her. In Marion's residential home the manager had taken account of the age and ability of the residents and had organised in-house exercise:

> "*Fergi [paid-carer]: What we do is talk about it [the need for exercise] here and we have in-house chair aerobics. Tell Diane about keep fit.*"
> "*Marion: I do keep fit on a Wednesday and I do it here [at home].*" (Marion, interview, page1)

This suggested that the amount of exercise undertaken by the women was dependent on having someone to escort them to access facilities and the motivation of the women and the paid-carers. This helped to explain why so many women named walking as their main form of exercise.

In summary, few women were exposed to the risk factors of breast cancer, drinking and smoking. The risk factor of a sedentary lifestyle was a concern, given that access to leisure centres or regular exercise depended on the motivation of the women or paid-carer to assist with this.

4.2.2.   Eating for health

This sub-theme explored the way food is used within the care sector as a reward. It served as a vehicle to address the issue of keeping healthy and warranted a sub-theme because food was seen as an important part of the women's culture.

The way the women interpreted keeping healthy, especially the seven women who did not need prompting, was through their diet. It was not surprising that these women viewed health in this way since my field-notes and observation

identified that diet and food was often used by the paid-carers as a means to convey and reinforce the 'health message'.

> *"Veronica [paid-carer] said all the menus had been completed last night because the shopping would be done today. When she did the menus she sat the residents down and asked them what they wanted for their meals. 'We talk about health, what is good for them and get them to think about their health and their meal' she said."* (Jane, Observation1, page1)

The women's responses (prompted and unprompted) to questions about keeping healthy demonstrated their knowledge about having a healthy diet since they cited the importance of low calorie drinks, fruit and vegetables being good for them.

> *"We eat salads and I don't eat snack before I go to bed."* (Tanya, interview, page1)

> *"I eat healthy foods don't I Meredith."* (Irene, interview, page2)

Although these responses typified the answers the women gave, Rona, who like many of the women named a number of healthy food options, also declared that her favourite 'healthy' food was "macaroni cheese". Similarly, Helen described 'healthy foods, such as salads, but added "but I love mince and tatties". This drew attention to whether the women really understood the value of the foods they spoke about. Honey, for example, was clearly having difficulty understanding the health message about eating five portions of fruit and vegetables a day.

> *"You are supposed to eat a lot of fruit and vegetables. You're supposed to eat about five portions, well four portions, five portions of different fruit. I mean, how can you eat five portions of fruit in one day?"* (Honey, interview, page1)

Her understanding was perhaps no different to people in the general population but demonstrated the difficulties in translating a health message not only to the

general public but also people with LD. For Vera the message was clearly ingrained, as any questions about keeping healthy were met with the same reply.

> *"I eat food, soup, diet coke and eat brown bread.*
> *I poo after eating brown bread."* (Vera, interview, page2)

Although Vera clearly associated brown bread with defecation, it is less clear whether she really understood the relationship between defecation and high fibre and bran contained in brown bread. It was also unclear whether she could transfer this knowledge equally to brown rice or pasta, although she spoke about brown as opposed to white bread and diet coke rather than full-sugar coke.

Trying to eat healthily was also compounded by the women's lack of cooking skills and the skills and knowledge about nutrition of their paid-carer. A related issue for some of the women was being over-weight. Morag and Pippa both lived alone and were overweight. They received help from Ronnie, a CLDN, who came every two weeks to monitor their weight. For Morag, living on her own meant she that she was able to eat between meals; she had put on weight because she used to go to the shop and buy a roll. The staff now monitored this and did not allow her out to the shops to buy snacks.

> *"Morag told Ronnie that the staff had stopped her eating filled*
> *rolls in between meals and had told her to 'cut out the cakes*
> *and biscuits' as they were bad for her."* (Morag and Ronnie, Observation1, page1)

Pippa had recently been in hospital and had put on weight due to the side effects of medication she was taking. She was also being visited by the CLDN, Ronnie, to monitor her progress and to support her through breast screening.

> *"Ronnie asked Pippa what she had done to keep her weight down, reminding her it was important due to the medication and her health. Pippa said she'd been walking more ... The staff were helping her with low fat meals, one paid-carer had made her low fat rice pudding and she had put strawberries in, and this was described as 'delicious'."* (Pippa and Ronnie, Observation2, pg2)

For both women, the paid-carer's influence was significant and demonstrated the importance of interdisciplinary working to support the women. Ensuring that weight loss was maintained would be an on-going goal. However, for people with LD maintaining a healthy body weight was difficult as there was a culture of eating out.

An integral part of the culture observed and spoken about was going out for a coffee or a meal. This was seen in a number of situations: for example, when the woman had an appointment there was often a 'treat' afterwards, while at weekends the women also received a 'treat'.

> *"Helen: The treat afterwards [going for breast screening]*
> *DW: what treat is that?*
> *Helen: Coffee or a cake."* (Helen, interview, page3)

> *"Jane: Sometimes a get a treat when I'm in on a Saturday I get a treat*
> *DW: what's your treat?*
> *Jane: Chocolate and marshmallows and sometimes a cake."* (Jane, interview, page2)

Here the 'treat' was seen as special thing and would always involve food or drink. In my reflective-diary and in the observations, I identified shopping and having lunch out as being 'special', as it seemed to be the highlight of the week for some women. This was reinforced by Veronica (paid-carer) during a conversation after I had observed her.

> "Veronica said that going shopping 'this is a big event as everyone wants to help'. They go to the supermarket and they will have a coffee there. 'It is a big event'." (*Jane, Observation1, page2*)

In summary, there was an importance placed on food and diet in this group of women. Food was used by the paid-carers not only to discuss the health but also used as an incentive to encourage the women to attend appointments. This helped to explain why some women viewed keeping healthy through their diet.

4.2.3.   Checking for lumps

This sub-theme explored whether the women monitored changes in their breasts. The women were initially asked whether they knew why women had their breasts checked. Five women reported that they didn't know why; seven reported that it was to ensure they were healthy; and four also mentioned cancer within their replies. The women were also asked if they checked their breasts and eight women reported that they did. Two women said that their paid-carers checked their breasts when they assisted them with their personal hygiene.

> *"Staff look after that. Checks are done when I*
> *am dressing... they are checked every day."*
> (Wendy, interview, page2)

Undertaking personal hygiene was thus seen as providing an opportunity for paid-carers to observe for changes in the women's breasts. However, not all women would receive or need help with personal hygiene. The remaining six women all said that they checked their breast themselves. Tanya, Honey and Irene disclosed that they checked their breasts every day. Pippa and Marion did not disclose how often they checked them while Rona reported that she only checked her breasts when she remembered:

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> *"Rona: Yes I check them; I look at them and feel them.*
> *DW: How often do you check your breasts?*
> *Rona: I don't know when I think about it."* (Rona, interview, page2)

The six women who checked their breasts themselves were also asked what they checked for. While Pippa, Marion and Irene responded that they checked for 'lumps', Marion and Irene gave very detailed responses.

> *"Irene: I check them over for lumps under there [goes under breast] and under there [under her armpit], and I tend to sorta feel it under the lymph nodes, the lymph nodes, to see if there are any lumps under there.*
> *DW: and how often do you do this?*
> *Irene: Every time. Even when I go in the shower, I go like this [demonstrated by touching breast and moving hand round to her breasts and armpit] for a check, 'oh nothing there', and a wee check here, 'oh nothing there'."* (Irene, interview, page2)

Marion was unusual, in that when the question 'do you check your breasts?' was initially posed Marion said 'no' but demonstrated with her hands what she did. This prompted me to ask what she was doing with her hands and this is when she told me about Dr George and how she checked for lumps.

> *"Marion: Dr George told me to check them for lumps. Dr George taught me to do this [actions checking the breast using the flat of hands to feel all over her breast]*
> *DW: That's good. And do you know why you check your breasts?*
> *Marion: To check for lumps."* (Marion, Interview, page2)

The detailed knowledge demonstrated by these two women may have stemmed from them having had problems with their breasts previously. Irene had been treated for breast cancer whilst Marion had bleeding nipples. The three remaining women had different answers from the other women. Tanya said that she checked for cancer, but was vague about what she looked for, but like Irene

had been treated for breast cancer. Honey explained how she checked her breasts in similar detail to Irene but did not mention what she was looking for, other than saying, *"if you got it you'll ken you got it."* However, she was aware of the consequences of not checking her breasts.

> *"It's always best to check all them [breasts] cause*
> *if you dinnae check it in a few years ... you could*
> *say "oh I've got it" and you might not be here in a*
> *few years."* (Honey, interview, page3)

Honey also avoided using the word cancer but elaborated that finding something could kill you. Her detailed knowledge stemmed from a women's health course she had attended at her day centre. In contrast, Rona said she did not know what she was looking for. This again demonstrated that although the women took on board health messages, they may not fully understand the implications of what was being explained.

Of the remaining four women, Helen was the only one who did not reply to the question other than to say that she would 'tell the staff.' The remaining three women all said they didn't check their breasts.

> *"No I don't look at them [and] I don't check them."*
> (Mairi, interview, page2)

This prompted all women to be asked whether they had received any information about keeping their breasts healthy. All replied that they had received information from either a paid-carer, a course or the GP practice. During the interviews, Morag highlighted the problem of retaining the information she had received.

> *"The nurse but I don't remember much what she*
> *said."* (Morag, interview, page2)

Morag's replay reflected the difficulties people with LD sometimes have with retention of information and may account for why some women are seen to lack knowledge. It may also have explained why Rona forgot to check her breasts regularly.

To summarise: knowledge about why women needed to have their breasts checked, and what to look for when checking their breasts was generally good in these women. With the exception of Honey, the women who had experienced breast problems demonstrated the most knowledge about how to check their breasts. This suggested that experiencing breast problems made the women more vigilant and knowledgeable. One woman also identified the difficulty of retaining the information she had been given. This suggested that regular up-dates about keeping their breasts healthy and how and what they should be checking for might be useful.

4.2.4.　Experience of breast problems

This sub-theme outlined the experiences of the three women who disclosed previous problems with their breasts. Marion had experienced bleeding nipples and found this an unpleasant experience.

> *"I had bleeding on my bra and on my nipple
> [touches breast to show me where]. It was
> horrible. I had blood everywhere... I was
> worried."* (Marion, interview, page3)

Her paid-carer took her to the GP and she was referred for a mammogram. Her mammogram indicated no malignancy and she has not experienced any further problems. This experience had made her vigilant about checking her breasts (as seen above). Tanya and Irene both had breast cancer resulting in mastectomies (removal of the breast). Tanya had undergone treatment for cancer two years prior to being interviewed after finding a lump in her breast. She had found the experience difficult to deal with as she thought she would die.

> *"I felt terrible when it was happening. I was upset
> at first because I thought I would die."* (Tanya,
> interview, page2)

She received a lot of support from the paid-carers during this time and her cancer was in remission when she was interviewed. She underwent yearly check-ups and mammograms at the breast unit to ensure the cancer had not

returned. Despite this, during the interview it was clear that Tanya was still worried about her cancer returning and that she might die.

> *"I am always checking my breasts to make sure*
> *there is nothing else there. I do that all the time."*
> (Tanya, interview, page2)

> *"Tanya was worried about her cancer returning and after the interview she said the hospital had said it might come back and this was still worrying her."* (Tanya, field-notes, page2)

Throughout the interview I checked with her if it was ok to talk about this and she said it was because she was more able to cope with it.

> *"I am strong and positive."* (Tanya, interview, page2)

Irene's story was different. Five years earlier her sister had been treated for breast cancer. Irene was not offered a mammogram, as would be the case for other women who had a sibling with breast cancer. The paid-carer queried this but it was not pursued. When Irene had found a lump in her breast she was in her mid 40's and her doctor thought it was an abscess and prescribed antibiotics. The lump remained and she was given more antibiotics. During this time she became unwell and again returned to her GP. She was referred to the breast unit where she was diagnosed with breast cancer. Despite this, Irene was very matter of fact about what happened.

> *"..Then they found out I had cancer of the breast.*
> *So they got me in right away to the hospital… and*
> *got it looked at ... It would have been going on*
> *and I would be riddled. It might have spread to*
> *the other breast."* (Irene, interview, page3)

Irene had a mastectomy and then began chemotherapy before having radiotherapy. She found this unpleasant and it made her feel ill.

> *"I felt really strange with the chemo and when I
> had radiotherapy it was like I had a night on the
> tiles."* (Irene, interview, page4)

Like Tanya, she now had yearly reviews to monitor her breast cancer. Again both Tanya and Irene were very vigilant about checking their breasts.

In summary, these women experienced a number of breast problems and this affected how they viewed keeping their breasts healthy. It adds weight for the need to ensure they are aware of breast problems and that they have access to appropriate health care.

4.3. Breast screening

This theme described the women's understanding and experience of having breast screening. It reflected the interview questions that asked the women about their experience of the procedure and how they made decisions about their health. Data from the interviews was again supported by information from the observations and field-notes. '*Breast screening' is composed of* three sub-themes: '*Being persuaded to go'*, '*Going for breast screening*' and '*I won't go back'*.

Of the 12 women with LD who participated in the study, 10 were eligible to participate in the breast screening programme. Honey and Morag were under 50 years of age and therefore not eligible to attend, although as seen earlier Morag had been diagnosed with breast cancer. Of the 10 eligible women, Rona and Wendy had not been to breast screening. Rona's reasons for not attending were unclear, while Wendy had refused to attend on several occasions. In total, nine women had been for breast screening and three had not.

4.3.1. Being persuaded to go to breast screening

This sub-theme identified some of the influences the women were exposed to when deciding to attend for breast screening. During the interviews, the women were asked to speak about their experience of breast screening and within their responses they discussed making the decision to attend. This decision was

only initiated on receipt of the invitation to go for breast screening. Three women, Jane, Wendy and Marion, remembered receiving this letter. Jane and Marion's paid-carers dealt with the request and discussed it with them.

> *"I got a letter ... and I think staff took it. At first I*
> *dinnae want to go and staff says "Jane you got to go"*
> *and explained things to me."* (Jane, interview, page3)

This quote sheds light on the process from receipt of the letter of invitation to presenting for breast screening. Despite Jane's reluctance to go, the paid-carer believed she should attend and explained what the letter was about. During the interviews the women were asked whether they made the decision about participating in breast screening and all replied they did. Wendy was a good example because she had received a number of letters inviting her to attend for breast screening and she had chosen not to attend breast screening. Furthermore, Wendy's CLDN had also tried to persuade her to go and had been unsuccessful.

> *"I just dinnae want to go to ... I have had letters*
> *and letters and I won't go."* (Wendy, interview,
> page3)

> *"After talking about checking her breasts Clary asked about*
> *breast screening. Wendy replied that she 'wasn't wanting to go*
> *for screening'. After the observation, Clary said that they had to*
> *respect the woman's decision, although she would keep*
> *reminding her about this and this would ensure she was vigilant*
> *about her breasts."* (Wendy and Clary, Observation1, pg1)

This observation showed that although the women may not have attended for breast screening it was not removed from the health agenda. Clary reminded her about the importance of checking her breasts. During the interview with Wendy her reasons for not attending became clearer. A powerful deterrent had been her friends 'hear say'.

> *"Friends told me, it was awfully sore. So I said 'well I'll not be going for it. Never in my life for that'. That's what has put me off."* (Wendy, interview, page4)

Clearly her friends had found the experience of breast screening unpleasant and this had impacted on her decision. To compound the matter, Wendy had also experienced a number of episodes of poor treatments when attending other hospital appointments which had a profound effect on her.

> *"Wendy: I was supposed to get the [Botox for the bladder] 'cause they couldn't find the notes, they couldn't do it. Three o'clock in the afternoon, that's when they took me down. They started to do it without anaesthetic, oh my god I was screaming the place down.*
> *DW: I guess you have had some poor experiences of hospital?*
> *Wendy: Yes I have and it has made me frightened of going in these places."* (Wendy, interview, page 4)

Wendy obviously felt disempowered by this experience and admitted this had made her scared of hospitals. Her decision not to attend breast screening was clearly influenced by the experiences she described. Two other women also spoke about the way they were treated when attending health appointments but this was not seen to affect their decision to go for breast screening.

Rona had spent some time in hospital because she broke her leg and reported not liking the hospital she stayed in. Like Wendy, Rona had not attended for breast screening. When asked if there was anything stopping her from going to breast screening, she never mentioned her hospital experience as a reason for not going. Despite several attempts to probe her about not going to breast screening during the interview, the cause of her reluctance to go could not be established. When asked what would encourage her to attend for screening, she believed she could not be persuaded to go to.

> *"I don't think nothing would make me go."* (Rona, interview, page 2)

This was important as it demonstrated that there may be no underlying reason for not going. In contrast, Honey's experience about not being understood by the doctor's receptionist did not deter her from wanting to attend breast screening.

> *"Touch wood when I get to 50 I'm definitely gonna go for it."* (Honey, interview, page 2)

Honey had also been on a course which had raised her understanding for the need to check her breasts. Unlike Wendy, these women had only had one poor encounter during previous appointments. This suggested that it may be repeated incidents of poor treatment and severity of this that deterred women from going for breast screening.

In summary, the women identified that they made the decisions to go for breast screening although this was not without external influences. Paid-carers were identified as being a source of influence and used their skills in explaining the procedure to help the woman make an informed decision. Although three women reported having poor experience at previous appointments, only one woman said this had influenced her decision not to go to breast screening.

4.3.2.   Going for breast screening

This sub-theme explored the women's experience of having a mammogram. All the women in the study who had been for a mammogram had been accompanied by a paid-carer. The role played by the paid-carer varied and depended upon the woman's level of disability. Broadly speaking, Irene, Tanya, Pippa and Jane were very able and articulate women and described the role of their paid-carer as taking them to the breast screening centre and giving them 'moral support'.

> *"My staff from 'Lincoln Road' go with me. The staff gave me a lot of support."* (Tanya, interview, page3)

The other five women were less able to articulate their needs. The paid-carer not only ensured they got to the screening centre but also assisted them through the procedure.

> *"Staff came with me ... We went by car. They helped me undress."* (Mairi, interview, page2)

Apart from escorting the women to breast screening, the paid-carers played a key role in supporting them through the procedure. This suggested that reassurance was important for women with LD. In order to understand what the women experienced during mammography, they were asked to describe what having a mammogram was like for them. For all women having a mammogram they have to undress and stand naked from the waist upwards in front of stranger and three women in this study found this embarrassing.

> *"I had to take my top off ... I felt embarrassed."* (Helen, interview, page2)

In addition to being semi-naked, the women had to stand in front of a large x-ray machine. During the interviews four women mentioned their reaction to the machinery.

> *"Don't like it [mammogram machine] I was scared of it."* (Vera, interview, page2)

> *"It was a big machine you go in it. I was a wee bit nervous I got over it though."* (Jane, interview, page2)

The unfamiliarity of the procedure, embarrassment and the machinery could constitute a barrier for women with LD. For Tanya and Irene they were less frightened of the machinery because they were more familiar with what would happen.

> *"I have grown quite used to it."* (Irene, interview, page8)

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Being familiar with the procedure was seen as a facilitator to the women having a more positive experience because they understood and knew what to expect. Having stripped and stood in front of the x-ray machine, the x-ray would be taken of the woman's breast. Below are typical responses from the women who described what having a mammogram was like.

> *"I didn't like it pressing hard. Don't remember anything else ... Glad it was over. I didn't like it pressing on me. It hurt."* (Vera, interview, page2)

> *"It's a bit sore having your breast put in [laughs] the machine. The worst thing is squeezing it. It's cold and painful."* (Tanya, interview, page2)

> *"It can be a bit cold and it's uncomfortable and it feels tight on your chest ... It feels as though one of the breasts is tight as if your breast is frozen. It's like a big lump of meat going through that big press and I have grown quite used to it, and I say 'oh, here comes the orange squeezer ... it's so sore."* (Irene, interview, page4)

These extracts show that the women in this study found breast screening an unpleasant experience. They remembered clearly the pressure and coldness. However, to lighten the experience, Irene had named the 'big press' the 'orange squeezer' and later called it the 'meat cleaver'. Despite understanding the procedure, she still found the experience painful and eight out of the nine women who had been for breast screening also described the procedure as painful.

> *"It was painful. It hurt."* (Pippa, interview, page3)

> *"It was sore when it pressed."* (Marion, interview, page3)

Jane was the only woman who described the mammogram as being '*ok, alright*'. The pain experienced by the women was not just the pressure on the breast. Four women found the procedure painful because they had to manoeuvre themselves or be manoeuvred by the mammographers into a certain position for the mammogram to be taken. They had to maintain this

position whilst the mammogram was completed and this often meant lifting their arm or stretching.

> *"I had to lean in and stretch my bad arm and it was sore."* (Helen, interview, page3)

For many women who may have arthritis or limited movement in their arm this procedure would be doubly uncomfortable.

In summary, mammography in this group of women was an unpleasant experience because of the embarrassment, fear of the machinery and the pain. All women had support and reassurance from their paid-carers who accompanied them.

4.3.3. I won't go back

In this sub-theme the women identified barriers and enhancers to attending breast screening. The women generally gave negative descriptions of breast screening and this was important in understanding what influenced the women to attend. For this reason the women who had attended breast screening were asked whether they would go back. Five women said they would not and Helen's response typified the reason why.

> *"No I wouldn't go back ... It was painful."* (Helen, interview, page3)

This response was important because it identified the parameters the women used in reaching their decision, i.e. polarised (painful versus not painful). This type of thinking was not seen in all women as two were undecided, but again the pain of the procedure was the thing that was most prominent when making that decision.

> *"I think the pain puts you off so I'm undecided. It does hurt and [there is] no guarantee it won't hurt so I don't know."* (Morag, interview, page4)

Pain was a deterrent for the women generally. However, women like Tanya and Irene, who had experienced problems with their breasts, were more tolerant of the discomfort the mammogram caused them because they were more aware of why they needed to undergo the procedure.

> *"It's a bit painful to put your arm up and stretched over. It's not for very long. I don't like having it done very much. I have to because it's important. I don't want cancer."* (Tanya, interview, page 3)

Having experienced cancer, Tanya was more aware of the consequences of not having a mammogram and clearly had the knowledge base to understand why it was important. For these reasons she could reconcile the pain with the necessity of the procedure. Understanding the reason for the mammogram was therefore identified as a factor in helping the women cope with the pain. Two women offered advice to other women about breast screening and both emphasised the importance of ensuring nothing was wrong.

> *"I would just to be on the safe side, go for a breast screening test because I have had that. I have experienced it and know what it's like."* (Irene, interview, page8)

> *"..If you go and you are alright, you are alright..... If you dinnae get checked you might not be here in a few years."* (Honey, interview, page4)

Another factor identified was the culture of mammography. The average time taken to complete a mammogram was approximately six minutes for each woman and any delays would mean that the next women would have to wait longer. It was therefore necessary to ensure the appointments ran to time. This identified a difference in cultures as the women with LD came from an environment whereby people worked around them and took things at their pace. When going to breast screening the women with LD would have to fit in with the appointment time and even a double appointment might not be enough to accommodate their needs. They would also need to adjust to the 'clinical' setting of the appointment.

> *"The ladies [mammographers] were nice, well I
> tried my best to talk to them, sometimes I found it
> hard, you're really in and out."* (Jane, interview,
> page3)

Jane explained that she was unable to chat to the mammographers as she would normally do, but rationalised that this was due to the length of the appointment. Not all women with LD would be able to do this or adjust to this environment as easily as Mairi demonstrated.

> *"I don't like going there [mammography], I was shaky
> but the staff [paid-carers] said to me not to be scared.
> The nurse [mammographer] said I didn't want it. But I
> did."* (Mairi, interview, page2)

Although Mairi had made the decision to have the mammogram, she was nervous about having it. Her paid-carers were more aware of her needs and tried to support and reassure her but the mammographers were less empathic towards her. The pressure of time and inexperience of working with women with LD could have been contributory factors to this. Better understanding about the needs of women with LD may have made this a better experience for Mairi. Or implementing the advice Wendy suggested.

> *"Even if Clary [nurse] can try and take me to
> see the place to see what I think. It would
> maybe be a bit of help to me."* (Wendy,
> interview, page5)

This again suggested that fear of the procedure was a factoring deterring the women from attending, while familiarity was important in facilitating attendance.

In summary, the pain of the procedure and the clinical setting were reasons why the women wouldn't have another mammogram. Knowledge and familiarity with the procedure were seen as facilitators.

4.4. Summary

This chapter gave an insight into the views of the women with LD about breast screening. Key aspects identified were that risk factors for breast cancer from

smoking and drinking were low but factors such as poor diet and lack of exercise were increased. Knowledge about health and breast screening was variable within the sample although retention of information potentially could account for knowledge. This suggested that reminders about checking the breasts might be needed. Paid-carers played a key role, as means of support, information and a potential influence in determining whether or not the women attended breast screening. The women's experience of breast screening was associated with embarrassment, unfamiliarity with the culture of breast screening, pain and fear from the procedure. Pain was the main deterrent to breast screening, although familiarity with the procedure underpinned by knowledge were seen to facilitate up-take.

Chapter 5:   Findings: The Carers

5.1.   Introduction

In this chapter the carers' views are reported. Carers were seen as an integral part of the support that women with LD received and would usually be the ones who would accompany them to breast screening. Thirteen carers participated in the study; the majority were paid-carers, with only three being family-carers. Unless specified, the carers' views were reported without differentiating between paid or family-carers. The paid-carers had worked with people with LD on average for 14 years[5] (range 2 and 17 years). All paid-carers had received mandatory training in health and safety, manual handling and food hygiene. Five did not disclose any training in health related matters, where the other five disclosed training on epilepsy or dementia because clients had these problems. Nicki and Janet who were residential paid-carers both from a social work funded homes said their training was not health related.

The carers' views were represented by two themes. The first theme, *'Doing the best we can'*, concentrated on the opening questions of the interview and was supported by data from the observations and field-notes. It explored the role of the carers and how they helped the women to keep healthy. This was analysed through the sub-themes, *'Care within boundaries', 'Keeping an eye on things'* and *'Food and health'.* The second theme, *'A few more difficulties'*, concentrated on the later part of the interview which asked about breast screening and making choices. Again, this was supported by data from the observation and field-notes. This theme explored how the carers explained breast screening, their influence in helping the women decide about having a mammogram as well as the women's experience of, and the barriers to, breast screening. The sub-themes that emerged were '*Trying to explain breast screening', 'It's their choice'* and '*The problems is ...'.*

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[5] one paid-carer did not disclose how long they had worked with people with LD

5.2. Doing the best we can

This theme embraced the problem of trying to monitor the women's health whilst working within the bounds of the carers' role. The first sub-theme, '*Care within boundaries*', explored how the carers interpreted their role in relation to health and identified the boundaries within which they worked. The second sub-theme, '*Keeping an eye on things*', looked at the how the carer's tried to monitor the women's health and the challenges this presented. The final theme, '*Food and health*', examined the culture of food within the care setting.

5.2.1. Care within boundaries

This sub-theme dealt with the carers' role in terms of their understanding of supporting the women in health matters. The cultures that the family and paid-carers operated within were different and for this reason their roles are presented separately. The unifying element that the family and paid-carers shared was that they both had undefined roles, especially in relation to overall responsibility for the health of the women they supported.

When the paid-carers were asked about their role and subsequently probed about whether they had a health remit, the discussions shed light on where the responsibility lay for overseeing the women's health. On one level it was found to reside with the paid-carers in the residential-setting rather than with those working in the day centres. Nelson and Margaret were the only paid-carers recruited from within the day centre settings. The culture of their working environments was very different. Nelson worked in an independent day centre and was responsible for a workshop that was run as a business to generate income for the day centre. In contrast, the day centre that Margaret worked in provided activities such as art, music and baking. Despite this, Nelson and Margaret saw health as the remit of the paid-carers within the residential setting but their reasons for this differed.

> *"It's this environment, we are the [factory] and we*
> *have to get certain jobs done so there is no time*
> *for health. Health is really the remit of the home."*
> (Nelson, interview, page3)

Nelson perceived clear boundaries about where the remit for health lay, the residential setting, and believed that health matters should be overseen there. This reflected normal working practice in that health matters would be the remit of the occupational health department. The day centre Margaret worked for was funded by the Social Work Department and it had set clear parameters about where the remit for health lay.

> *"For me there's a real spilt between social work*
> *and health even though we are meant to be this*
> *pretend one department and what one sees as a*
> *health problems can very often be left out of a*
> *day service provision because it's not seen as*
> *appropriate."* (Margaret, interview, page3)

Margaret's view shed light on the way that health was viewed by the Department of Health and Social Services and the culture within it. Again, the responsibility for health of the women with LD resided with the residential setting. The views of those working within the residential setting revealed another division about the responsibility for health. Within residential care, the remit for health depended on the 'home' culture. Six paid-carers saw health as their remit. Veronica worked in an independent residential setting and supported people with LD in their own home. She acknowledged that there had been a lot of changes in the responsibility within the care sector but saw ensuring the health of her clients as part of her role.

> *"There's a lot more responsibility on the carers*
> *now. It's not just cooking and cleaning but*
> *everything. Health is an important part as staff*
> *have to ensure the residents are well maintained.*
> *It's their job."* (Veronica, interview, page7)

Veronica worked within the boundaries she believed were associated with her role. The culture of the residential homes that Janet and Nicki worked in was

very different. Their posts were funded by Social Work and health was not seen as part of their remit.

> *"To be honest health isn't encouraged here. They told me I had to forget all I knew about health as it wasn't something I needed to know. Here it's about helping the person live independently and be independent."* (Janet, interview, page1)

Janet had been a nurse prior to taking this post and had been set clear boundaries. It could be argued that health and independent living are symbiotic because many aspects of being independent such as being able to go out into the community relied on being in good health.

Within these discussions, six paid-carers identified another layer of responsibility: that of the women's family. Where members of the family were involved, they were integral to any decision about the woman's health. The family-carers were seen to constitute two groups: those who worked with the paid-carers and those who did not.

> *"We have parents who ask us to check things out and work with them and then we have other parents who are appalled and clearly say don't even touch on this subject."* (Margaret, interview, page5)

> *"We often get a note back from parents saying had we noticed this problem and telling us to get this checked out with the doctors because they have told us we have to do it, even when we think it's nothing and would watch and wait."* (Emma, field-notes, page2)

Emma demonstrated the blurring of boundaries between herself as the woman's carer and the family-carer as the parent. These intrusions were often difficult to manage. Three paid-carers welcomed family involvement because they could establish whether things such as breast cancer ran in the family.

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> *"Checking with the family to see if there is a history."* (Maureen, interview, page 4)

Four paid-carers suggested that family-carers were uneasy talking about health problems with them.

> *"Parents will take it more seriously if it comes from a doctor than from us."* (Janet, interview, page5)

> *"I think sometimes parents put more credence on health issues being spoken about by health professionals rather than support workers."* (Elaine, interview, page3)

Reasons for these views were not explored with the paid-carers, although they suggested that family-carers differentiate between health and care roles. This might have been due to the perception of care work, which is often associated with a low status, limited training and a high turnover of staff. Another problem mentioned by half of the paid-carers in this study was the lack of continuity of staff and the impact this had on the women's health.

> *"If you are in any private rent or residential setup you will have continuous flow of staff, you are there one week or not there the next. You realise how important it is to have that continuity and have that information passed on."* (Margaret, interview, page4)

In this study, the average length that the paid-carers been working in the same post was 5 years but ranged from 1 year to 11 years. It was evident from what the paid-carers said that not all organisations had such long-serving staff. The advantages of having regular paid-carers were that they got to know the women and were better placed to monitor any changes in health or behaviour.

> *"The residents appreciate continuity and know who's looking after them. You can also monitor how they are doing. In other places you can't and things get missed."* (Veronica, interview, page11)

Veronica's point about things getting missed was important. Monitoring the person would identify potential health problems but being informed of problems was just as essential. A problem identified by five carers in this study was the poor communication within and between the care sectors and the family homes.

> *"It's so difficult, sometimes they don't tell us that they have diabetes or epilepsy ...or we'll get a note saying that they are on a diet or that they have diabetes and to watch how many biscuits they eat."* (Nelson, interview, page4)

> *"There are boundary issues, do you approach a carer when you first notice something or do you wait until they say something to you about them not feeling unwell."* (Elaine, interview, page4)

The consequences of information such as the person being a diabetic or feeling unwell not being passed on could have an impact on the individual. Elaine suggested this might be due to boundary issues with the carer sectors operating independently of one another. This made communication difficult as the culture of each sector varied and passing on such messages might be construed as interfering or checking up on the other sector. This helped to pinpoint some of the problems with communication within the care sector.

Similar problems over the definition of their role were found within the family-carers. All three family-carers in this study were female. Heather was retired and lived with her husband and daughter Holly, whilst Vicki's daughter Jen had recently moved into residential care after leaving school. Kirsty looked after her sister Honey at home with her brother Peter. Both Kirsty and Honey had LD. The role of the family-carers was the most complicated. They had the relationship of parent or sibling, but were also a carer which meant that the relationship and boundaries between these roles were constantly shifting.

> *"I am Honey's sister. I am also her carer. I look after Honey's well being, her health.*" (Kirsty, interview, page1)

Looking after the woman's health was seen as part of both roles (family member and carer) and meant that they were involved in decisions about health. Once the woman reached 16 years of age the boundaries changed, since in law any woman with LD (or man with LD) was seen as an adult. This period signalled two major adjustments for the family-carers. The first was the transfer out of children's services into adult services, a process known as 'transition'. This often this meant a culture change for family-carers, as they had to adapt to a new way of working with services. A pertinent example was moving into adult services which meant that there was less monitoring of the young person.

> "*It's worse when they move to adult services, there's no-one checking up on them. You used to get people in the school, a health visitor or social worker, but there's nothing like that when they move.*" (Heather, interview, page5)

Moving from a culture where different services checked-up on each individual to a service where there was relatively little input was a huge culture change for the family-carers. Heather recognised that there would be less monitoring. Given her daughter had mobility, heart and mental health problems, she was concerned her health would decline. Transition also shed light on the reasons why family-carers asked for things to be investigated and why they were unlikely to discuss health problems with the paid-carers. Kirsty's situation was different to Heather and Vicki because she also had LD and received a lot of support from the community LD team. When she had problems supporting Honey she would always consult them about any worries she had.

> "*We would go and speak to Sally [CLDN].*" (Kirsty, interview, page4)

The second change that occurred for some family-carers was relinquishing the role of decision maker if the woman with LD had capacity. Heather's daughter Holly had capacity and now made her own decisions. For Heather this meant she was no longer part of the decision-making process.

> *"When they move into the adult services they [the woman] are in charge and we get to know nothing. We have to ask. So it's hard. We can't interfere."*
> (Heather, interview, page5)

This was a difficult adjustment for Heather to make but also identified some of the problems family-carers faced as their off-spring matured. Vicki and Kirsty had taken a different approach, and chosen to become welfare guardians, although Kirsty was still awaiting her final papers. Welfare guardianship enabled family-carers to remain involved in decisions.

> *"When the letter about the smear test came through they automatically phoned me and said 'What would you like to do about this', because I'm still her care-guardian."* (Vicki, interview, page7)

Having welfare guardianship enabled the family-carer to oversee the care given to the family member and ensure their health was being monitored. With the exception of Kirsty, Heather and Vicki identified the difficulties of their role as a carer for a woman with LD who remained within the family home. Heather, for instance, used to have Friday's alone with her husband to go out, but Holly chose Friday as her half-day from her work to join them, whereas for Vicki her daughter's the level of disability meant she was constantly 'on the go'.

> *"I mean we are retired, we still want to do things. We go out on a Friday but sometimes we are stuck, we have to come home early for her."*
> (Heather, interview, page4)

> *"It's a big burden on a family with a person of that level of disability."* (Vicki, interview, page7)

Both these carers spoke about the unseen burdens of continuing to support their off-spring especially on elderly parents.

In summary, the roles of the paid and family-carers were very different but both roles had no clear boundaries. The way the responsibility for health was

interpreted could have an impact on the health of the people they supported. For the paid-carers the way their work was organised potentially had an impact on the health of the individual they supported.

5.2.2.   Keeping an eye on things

This sub-theme encapsulated how the women were supported in keeping healthy. It also identified some of the difficulties the carers had in ensuring the health of the women they cared for.

When asked how they thought women with LD kept themselves healthy, all the carers acknowledged this was difficult for the women because they had little insight into their health. This was especially pertinent for the less able women since they lacked the communication skills to report problems.

> "*It depends on the level of their disability and I mean from my point of view it's having people around to monitor her as she's not able to monitor herself.*" (Vicki, interview, page4)

> "*You have to be vigilant as they cannot communicate ... and have so little language and understanding." (*Sandra, interview, page2)

> "*We assist with her shower ... so I suppose if anything was noticeable we'd see it right away.*" (Emma, interview, page2)

All carers said that they undertook some form of surveillance of the women's health, including those who said that health was not their remit.

> "*If there is something then I'll mention it.*" (Nelson, interview, page4)

Six carers noted that not all the women needed help with personal hygiene and this placed them at a disadvantage, since potential health issues might go undetected.

"We don't know what their skin is like, whether there is a rash or it is dry. Things like that that could be important." (Fergi, interview, page4)

This demonstrated the differences in boundaries between health monitoring in the more able and less able women as carers had to respect the autonomy of the former. Similarly when the topic turned to how the women kept their breasts healthy, nine carers acknowledged that some women with LD would not be able to undertake breast checks themselves. Generally, the women unable to undertake breast checks relied on their carers to help them with their personal hygiene. This allowed the carers to monitor the women's breasts for changes. The more able women were again disadvantaged because none of the carers were sure how often or whether the women actually checked their breasts.

"I'm not sure she checks herself [breasts]. She says she does, but what she says and what she does are two different things." (Heather, interview, page2)

This raised the issue of acquiescing. However, the carers had to respect the women's dignity and autonomy and so were unable to carry out independent surveillance. For those needing personal care, observation of the breast was the current advice from the NHSBCSP, and all the carers were aware that they should not be undertaking any physical examinations. Within the interviews, five carers described how they undertook discrete checks during the washing or drying routine of these women.

"When you are drying you are aware of anything very obvious or a change or if there was a lump [in the breast]." (Elaine, interview, page4)

This type of care was unacknowledged and was undertaken to ensure the women kept their breasts healthy. It also identified their knowledge of breast awareness. Again, the problem of observing the breast was more problematic for the carers who supported more independent women since they would not assist with personal hygiene. This prompted three carers to ask whether the women would report a lump in their breast.

*"I don't know what she would do if she did find a
lump. I wonder how many would come and tell you,
or would they leave it so it fungates [tumour breaks
through the skin]?"* (Janet, interview, page3)

The carers who raised this question all believed the women would come and talk to them about this and this was supported by Helen in the women's views. This led on to asking the carers where they thought the women obtained their health knowledge from. Six carers thought the source of the women's knowledge was informal, especially through television soap operas.

*"One of my clients I can imagine her picking
perhaps something up from the TV."* (Elaine,
interview, page5)

*"They are really influenced by the TV especially
East Enders. This is where they get the
information from and they really believe this."*
(Nelson, interview, page4)

The soap operas were popular with the women and when arranging interviews the women would ask for their appointment to be made around them. The belief in what they saw was also true of television advertisements. For example, Veronica said that the women ask her to buy the cereal 'Special K' when shopping because they believed it caused weight loss. This demonstrated their lack of awareness, since this would only occur if the cereal was part of an overall diet. The remaining carers spoke about more formal channels such as attending groups at the day centre, talking to the carers or going to the health centre.

*"Apart from the nurse up at the health centre ...
maybe day services, a women's group or
something."* (Emma, interview, page4)

*"Sandra: from us really.
Maureen: we do our best and get input from the
LD teams and we talk about it."* (Sandra and
Maureen, interview, page2)

> "*You sometimes get information at the health
> centre when you go to the desk they have wee
> leaflets.*" (Kirsty, interview, page4)

There seemed to be no consistent means of obtaining information, which prompted Margaret to suggest it was 'pot luck'. This finding helped explain the variation in knowledge found within the women and suggested a more consistent approach to health education was needed. An interesting finding was that Kirsty was informed how to keep her breasts healthy from her sister Honey who had attended a day centre course.

> "*Honey did that last summer and it was Honey
> that telt me that [how to check the breast].*"
> (Kirsty, interview, page2)

This was perhaps an unusual situation, as Kirsty was Honey's guardian but she also had mild LD. The carers did not mention the women talking to their friends about any health problems. Most of the women in this study had previously lived in long-stay hospitals where they would have had access to other people to talk to. This would have been similar to the group houses that some of the women lived in. Those women who lived alone or received one-to-one care were more isolated as their time was spent mainly with the paid-carer or on their own.

> "*I don't really think many have what you and I
> would call friends, it's more likely the staff, their
> family or the GP.*" (Nicki, interview, page6)

> "*She has my friends but they are old like me.*"
> (Heather, interview, page9)

This was significant since it indicated that the women had few independent sources of support outwith where they lived.

In summary, monitoring the women's health and breasts was easier in the more dependent women due to the need for assistance with personal hygiene. For the more able women, health problems could be missed because of their independence with personal hygiene. Furthermore, health education was found

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to be inconsistent which suggested that some intervention was needed to ensure the health needs of the more able women were not being missed.

5.2.3.   Food and health

This sub-theme explored how the carers encouraged the women to keep healthy and this was seen to be by reminding them about diet and exercise. A healthy diet was cited by all the carers as a way of keeping healthy.

> *"We review their diet and keep an eye on what they cook for themselves. We try and suggest that healthy is fruit and not biscuits."* (Janet, interview, page3)

> *"We keep an eye on their diet we have a dietician and make sure the food is good."* (Maureen, interview, page3)

Diet was used to explain health and helped to explain why the women viewed health through their diet. Similarly, the meals cooked for the women would depend on the skills and dietary knowledge of the paid-carers.

As demonstrated in Chapter four, many of the paid-carers' routines and activities centred on food. For example, I was invited to have coffee with Fergi (paid-carer) and Annie (a woman with LD) after observing them at the breast screening unit. This was Annie's 'treat' for going. Veronica also invited me to have lunch with them at a garden centre.

> *"..Veronica invited me for lunch at the garden centre, she told me they met once a week here with the residents and other members of staff. She explained that this was a treat and the residents were taken for coffee because they helped them with the chores or after a doctor's appointment for being good..."* (Veronica, field-notes, page1)

The culture of food was also reflected in the way managers suggested I recruited the women. Three managers asked me to have coffee or lunch with them and the women as a means of getting to know them better.

> *"...Simon suggested that I had lunch with him and some of the women so they could talk to me about the project informally..."* (Vera, field-notes, page1)

Six carers raised concerns over the women's diets because of their propensity to put on weight and the consequent effect on the women's health and mobility. Monitoring what the women ate was seen as easier in the group homes than for those women who lived alone.

> *"We try and promote as much healthy eating as is possible, but when we're not there, if they want to eat the bars of chocolates or the cream fair enough ..."* (Veronica, interview, page3)

> *"Jen knows fine that eating a whole chocolate cake is not good for her but it doesn't stop her doing it."* (Vicki, interview, page3)

The scenario Veronica described identified the difficulty the carers faced with supporting people who lived independently within the community. Although they could empower the women to eat healthily by giving them information, there was only so much that could be done without encroaching on the woman's autonomy and trust to enforce it. As Vicki suggested, the women did not always act on or apply the knowledge they had. A comment by Nelson during the interview suggested another point of view: that people with LD do not have partners or have sex hence food becomes a substitute for this. He was the only carer to suggest this but there may be some support for this given work on comfort eating. One way to manage weight problems was to take exercise. Six carers identified the activities they had in place for the women they supported, ranging from in-house aerobics to activities within the day centre. The point raised by two carers was the difficulty in engaging the women in exercise.

> *"We have initiatives such as healthy eating and exercise and get them out for a walk ... but it's not always feasible."* (Emma, interview, page3)

Emma mentioned that if they were short staffed or the weather was poor a walk was not always possible. Heather raised a potential difficulty for many disabled people.

> *"She enjoys swimming, but it's the getting in.*
> *She needs to be hoisted ... and there aren't the*
> *facilities as few places have hoists."* (Heather,
> interview, page6)

Lack of specialist equipment was preventing Holly from swimming because neither Heather nor her husband were able to lift her in and out of the pool.

In summary, food was an important element in the carer's culture and was used to reinforce the health message. A key factor identified was the tendency for women who lived alone to over-eat which impacted on their health. This suggested they did not apply their knowledge about health to their own situation. A compounding factor was the limited access to exercise facilities which was exacerbated by the constraints on the carers and the motivation of the women.

5.3.   A few more difficulties

This theme explored the how the carers explained and supported the women to make the decision to attend breast screening. The sub-theme '*Trying to explain breast screening'* examined the difficulties of explaining breast screening to the women while the sub-theme '*It's their choice'* looked at influence the carers had on the women's decision about breast screening. The final sub-theme, '*The problems is...'*, focused on the carers' perceptions of the woman's experience of breast screening and the barriers that prevented them from attending.

5.3.1.   Trying to explain breast screening

A generic difficulty mentioned by all the carers about people with LD was the problem they had in understanding what was being said.

"Understanding is a problem for this group."
(Maureen, interview, page1)

*"When you talk to them you never know what
they take on board."* (Nicki, interview, page8)

The problems with understanding meant that all the carers had to develop skills and knowledge to explain things to the women. A common element used by all of them was tailoring what was to be discussed to the level of the women's disability. Seven carers also suggested that getting to know the women helped them to pitch information at the appropriate level.

"*The longer you work with the guys, you get to
know them, inside out, but it's the communication
that's the hardest part."* (Emma, interview, page5)

However, for those carers supporting women with severe and profound LD, the problems in explaining things were magnified. Elaine worked with a woman who had a profound LD and openly admitted the difficulty she would have in explaining breast screening to her.

*"The woman I work with most of all has a very
profound learning disability but I don't think I would
personally know where to begin trying to explain
breast screening to her."* (Elaine, interview, page2)

For those carers who worked with women who had severe and profound LD they often had to make the decision for the woman because these women would not have capacity to consent to such procedures themselves. Sandra and Maureen worked exclusively with women with severe and profound LD:

*"Sandra: We have not tried to explain breast
screening if we're honest."*
*Maureen: If we did, we would involve the
Community Learning Disability Team, and see
whether we should do this and seek more
information about this issue. We would have to*

decide about the distress this would cause ... as they would need to sedate our clients." (Sandra and Maureen, interview, page1)

These carers enlisted the wider team to explore the situation, with the aim of not causing the woman undue distress. As Maureen suggested this might entail the use of sedation on people who found medical appointments upsetting. Four carers mentioned this when interviewed:

"..Sedation might be a potential barrier? Maureen mentioned sedation for women who needed dental treatment. So did Veronica with Shelly who'd always been sedated for her cervical smear. Sandra and Elaine had suggested this was why procedures like breast screening weren't prioritised – juggling the risks against the distress in their clients?" (Sandra and Maureen, field-notes, page2)

The need to sedate women was identified as another barrier to breast screening. When asked 'how would they explain breast screening to the women', only three carers had discussed this with the women they supported. Despite this, all carers offered ideas about how they might approach this subject. Three said they would be cautious about mentioning cancer because of the fear the word 'cancer' instilled in people.

"I think people who have knowledge of a member of their family dying of cancer that would be very scary because that's their only experience of it." (Nicki, interview, page1)

"Cancer frightens people." (Maureen, interview, page2)

"Whether cancer means anything is debatable because 'cancer' the word can instil a huge amount of fear but I can honestly say with a whole lot of our service users it would mean absolutely nothing, it could be broccoli." (Margaret, interview, page2)

Margaret acknowledged that for her clients the word 'cancer' would be meaningless and this reflected the different disability levels the carers worked with. The way the carers said they would describe breast screening varied. Five carers mentioned using pictures and information leaflets to reinforce what was being discussed. Pictures were seen as useful because the women could visualise what was expected of them.

> *"A leaflet that has pictures on, that I could actually explain along with the pictures of what it entails... Discuss how some people get problems with their breasts in their later life and things like that and that breast screening prevents that."* (Nicki, interview, page1)

Three carers spoke about getting other people to talk to the women.

> *"I would think about bringing in someone getting the doctor or the nurse just to tell you about it."* (Elaine, interview, page9)

> *"It would be discussed with tenant to the best of our ability and then if we felt that wasn't being beneficial then we'd look for other sources to help them understand"* (Janet, interview, page5)

This demonstrated that the carers were aware that they might not be able to explain things fully and would seek out help to ensure the women understood what was being discussed. During the interview, Heather mentioned that her daughter had been visited by the nurses at home to talk about how to keep her breasts healthy. Although it was unclear who had made an appointment, Heather was not involved in their discussions.

> *"When the nurse came to tell her about her breasts, I mean, we're not involved. They went upstairs, and made it clear it's Holly they we're here to see. So if we don't know, how can we help?"* (Heather, interview, page2)

The nurse's priority here was to respect the woman's autonomy. This identified a number of boundary problems between the nurse, the woman and the parent. It also demonstrated the difficulty in supporting people with LD on health matters, not only for nurses but also parents.

The terms used to help the women understand breast screening were typified below.

> *"I think there would be looking for lumps and bumps and then maybe explain to them if something is found they have to go back."* (Fergi, interview, page1)

> *"I would say that some people feel it is uncomfortable others say it can be painful. I'd be telling her there will be a machine that will come down and squeeze her breast. I would say that some people feel it's uncomfortable others say it can be painful. I would be reassuring her though as well."* (Janet, interview, page4)

> *"Veronica explained in simple terms such as 'to try and see if there is anything wrong with your breasts'. 'They want to take a picture and have a look inside to see if there is anything wrong'. 'They just want to see if everything is ok so you don't get ill'."* (Observation, Veronica, page2)

The descriptions of the procedure offered contained varying degrees of detail which helps understand the different information the women received. During the interviews, only four carers mentioned that the women might find the procedure painful or uncomfortable. However, pain was identified as an issue by women in this study who had undergone screening. Fergi was also the only carer who mentioned that the women might have to go back if something untoward was found. This would be important especially if the woman found the procedure painful, since this might deter her from attending again. Within all the descriptions about having breast screening, the carers reinforced the need for reassurance.

> *"Reassurance would be a big thing as it's important as it's hard to explain exactly what will happen as they don't really know."* (Janet, interview, page6)

> "*The challenge is to get them to understand ... and not to frighten them and reassure them. It's difficult to get that balance."* (Emma, interview, page2)

Getting an appropriate balance of information, as Emma suggested, was often difficult. Mention of pain or cancer were factors that might deter the women from attending.

In summary, explaining breast screening was difficult due to the inherent cognitive problems. To help the women understand what was involved, the carers used their knowledge and skills to explain in the best way they could. Pictures were often used as means to explaining what would happen. A key finding was that the degree of detail given to the woman depended on the carer's knowledge and the woman's level of understanding. A central feature within the discussions was the reassurance given to the women by the carers.

5.3.2.   It's their choice

This sub-theme explored how the carers supported the women to make the decision about participating in breast screening. All the carers believed that women with LD should be offered breast screening.

> *"I think it's very important for all women and every woman is entitled to this care and the check up regardless of whether they have got mental health [problems] or not."* (Emma, interview, page2)

> *"I don't think that they are any different than any other women. Obviously they have a few more difficulties but then things should be in place before they attend."* (Janet, interview, page5)

The carers all acknowledged that there might be more problems for the women but that they should not be excluded on the basis of their LD or other health issues. Janet also believed that any issues should be ironed out beforehand. For most women, the process of making the decision to attend for breast screening commenced when the letter of invitation arrived. The letter was always addressed the individual woman and the carers would either intercept it or be told about it.

> *"When the letter arrives [we] take it from there."*
> (Sandra, interview, page2)

> *"I would really prefer if the letter comes to the staff ... They can worry about things for ages and you don't really know what they are worrying about."* (Janet, interview, page4)

Janet said she would prefer the letter to come to her first to stop the women worrying if they did not understand what it was about. This was important, especially for those women who were independent since they might forget to tell their carer about the letter. When discussing whether the women wanted to go for breast screening the carers generally discussed this together with the women. The exceptions were those who supported women with severe and profound LD.

> *"Sandra: If it needs to be done then well it has to be done in her best interest. It's difficult as the level of understanding is limited.*
> *Maureen: I think that's the same for breast screening."*
> (Sandra and Maureen, interview, page4)

Decisions here were made in terms of the woman's best interests, because the women were unable to understand what was being required. This meant taking a pragmatic approach, considering the consequences of not acting and balancing these against having the procedure. For the women who had capacity to make decisions, the carers were united in that whatever decision the woman made it had to be her decision and they had to respect it. To help the

woman make the decision a number of different approaches were used to discuss issues. An extreme example was recounted below.

> *"She [woman with LD] had received her letter for breast screening so Pat sat her down and said it's your invitation for breast screening. She said "I don't want that." So she put it in the bin."* (Emma, Field-notes, page1)

Although Pat asked the woman if she wanted to go to breast screening she made no attempt to explain what it was. If she had explained things to her and given her time to think about this the outcome might have been different. From the interviews within this study, Pat's method of discussing breast screening was the exception.

Those working in the social care sector also added that it was up to the woman to choose whether she wanted to discuss health matters.

> "*We have to ask them, we have to give them the right to choose if they want to talk about certain aspects of health*." (Nicki, interview, page4)

Here Nicki suggested that they could not force a discussion about breast screening. If the woman did not want to listen or talk about it then the topic of discussion was terminated. She also intimated that it was up to the client then to pick up the discussion, but this again presented difficulties such as remembering the topic. A consistent finding was that the carers were aware that the women were autonomous decision makers and that they should not make the decision on their behalf.

> *"You dinnae want to pressurise them to say to 'yes I'll do that' ... They have to be fine about this decision because we havenae the right to make the decisions for them."* (Fergi, interview, page7)

> *"We would always discuss things with them and they'd not be forced to go [to breast screening]. It would always be their choice."* (Emma, interview, page3)

This demonstrated the willingness of carers to respect the women and their decisions but it also identified where influences could be introduced. Five carers acknowledged that some women would always do what their carers or parents wanted them to do.

> *"It's the carer and parents that make the decisions,*
> *they [people with LD] always do what they say."*
> (Nelson, interview, page5)

> *"There is this huge push of acquiescence and 'I*
> *don't want to say the wrong thing' so if they look like*
> *they want that answer I will give that answer."*
> (Margaret, interview, page9)

In Margaret's description, she commented on the problem that people with LD often want to please, whereas Nelson suggested that parents disregarded the woman's autonomy. Despite this, six carers mentioned the influence that they might have on the women's decision and acknowledged that they had to be careful about this.

> *"I have the power really to talk you completely into*
> *doing something, every fibre of you says no I don't*
> *want to do it."* (Elaine, interview, page7)

In summary, there was awareness within the carers that they were a powerful influence on the decision made by the women. For the women who did not have capacity to make decisions, decisions were made in light of the principle of best interest. A key finding was that the decision-making process about attending for breast screening commenced with the letter of invitation. This suggested that education about breast screening might need to be undertaken prior to the arrival of the invitation.

5.3.3. The problem is...

In this sub-theme the experience of going for breast screening was discussed along with what prevented the women from attending. During the interviews

three carers disclosed that they had known and supported women with LD with breast problems. Nelson and Veronica had supported a woman with breast cancer, whilst Fergi had cared for a woman who had experienced bleeding nipples. When asked whether the carers had accompanied a woman to breast screening, only Fergi and Veronica said they had. Veronica's description was not very detailed but she did mention that in her experience some women were more confident and independent than others.

> *"Jane went through on her own whereas others*
> *would be wanting you to go through with them."*
> *(*Veronica, interview, page2)

This was an important message for service providers since every woman should be treated individually. Both carers emphasised the need to reassure the women and this echoed the reassurance given when they explained the procedure. Veronica described her experience of accompanying a woman to breast screening and how she offered reassurance non-verbally through the use of facial expressions.

> *"She was ooooh bit squealy and I think she was*
> *just relieved when it was over. So reassurance is*
> *important, I mean when she looks at you she can*
> *tell by your face that you are saying that's really*
> *good that you done that."* (Veronica, interview,
> page2)

> *"They then took a picture of the right side this was easier as*
> *Fergi was in Annie's line of vision. Again, the mammographers*
> *manually turned her head and interjected without giving praise.*
> *Fergi asked if she could help but was told 'no they had to do it'.*
> *They tried to get her into position. Fergi looked at me [seemed*
> *angry]. Fergi signed instructions as best she could throughout.*
> *Just as her breast was clamped Annie pulled away, so the*
> *procedure had to start again. There was more pushing and*
> *shoving by the mammogrpahers and little talking to Annie.*
> *Fergi and myself encouraged Annie and signed to her what to*
> *do. Annie counted, one, two, three. The picture was taken.*
> *The mammographers went away to look at the pictures."* (Fergi,
> observation1, page1).

Veronica described the experience of the woman she supported as being uncomfortable but reassurance was a key feature in supporting the women through breast screening. Fergi's experience was very different. She was accompanying Annie (woman with LD) who was going for her second mammogram. Fergi had informed the mobile unit that Annie had an LD and had made a double appointment. I accompanied them as part of my observation. I explained to the mammographers why I was there and they agreed to me observing them.

This observation documented one woman's experience of breast screening, but it also illuminated the cultural differences between the different actors. In discussions afterwards there were divergent opinions about this interaction.

> *"Annie said it was ok but was glad it had finished as it was sore. She didn't like the pushing and shoving either she wanted Fergi there because felt frightened."* (Fergie, observation1, page2)

> *"Fergi was annoyed that she was unable to give more assistance to Annie. She knew Annie was becoming upset because she started counting. She 'didn't like the manner' of the mammographers – 'they had not treated Annie with respect'. She was annoyed they didn't talk to her even when they pushed and pulled her about."* (Fergie, Observation1, page3)

> *"The mammographers spoke about the difficulty of getting women 'like Annie' to comply commenting "you see the problems we have"... (seemed negative?). She said that they don't always know who is coming but her records showed her as having been before. She spoke to Fergi 'we rely on people like you to help us.' ?this didn't reflect what they did during the observation. We chat about my project"* (Fergie, observation1, page2)

There was a clear lack of awareness from the mammographers about how Annie and Fergi had perceived this procedure. What this observation identified were differences between those who worked with people with LD and those that did not. Furthermore, Fergi was unable to offer the reassurance to Annie that she wanted to. The key message from these experiences was that reassurance was essential and mammographers should be aware of the women's needs.

Within the interviews around breast screening, a number of other barriers were identified by the carers. Parental attitudes towards breast screening were mentioned by four paid-carers.

> "*Some parents just dismiss the whole screening and sexual health thing totally, others are really good.*" (Nelson, interview, page4)

This raised an important issue in that often parents are not educated about screening or have reservations themselves. The women that the family-carers looked after in this study were too young for breast screening so insight had to be gleaned from their experience of cervical screening.

> "*Honey got a smear test done ... [she] didnae like that.*" (Kirsty, interview, page3)

> "*I mean the cervical smear was a bit of a disaster but well breast screening is less invasive so I'm not sure what she'll make of that.*" (Heather, interview, page3)

Both women's experience of cervical screening had been unpleasant but neither Heather nor Kirsty were against them attending for breast screening, although Heather had reservations about how Holly would cope with that. Honey, who was interviewed with her sister and carer Kirsty, was adamant that she would go for breast screening when she was old enough. Vicki was not dismissive of her daughter going for breast screening, but she was reluctant for Jen to go for cervical screening.

> *"I think with breast screening there would be a*
> *reason for that, but there might never be a reason*
> *for her to have the cervical smear."* (Vicki,
> interview, page2)

Vicki mistakenly believed that cervical screening was only for women who had engaged in sexual intercourse. Her concerns over Jen attending for cervical screening were related to her concerns over sex and sexual abuse. This became clear during the interview: she was convinced that if Jen went for a cervical smear it would confuse her about who could touch her vaginal area. This was a boundary Vicki did not want to cross. She was also concerned about her daughter being sexually abused, especially as she would not be able to vocalise this because of her limited communication skills. Vicki's concerns were genuine and helped to explain why some parents had reservations over screening.

Fear was another barrier identified by four carers.

> *"I think the main barrier is fear of the unknown*
> *really."* (Nicki, interview, page2)

> *"Fear of the procedure [breast screening] and*
> *worry, if they have never been before."* (Janet,
> interview, page2)

These carers raised an important point when they described the difficulties some women have when they are confronted with unfamiliar surroundings and experiences. This would be pertinent for women with LD who had never been for breast screening before. To compound matters, feeling vulnerable by having to undress could exacerbate feelings of fear.

> "*The problem with Rizz is that she doesn't like to*
> *take her clothes off in front of anybody ... she's*
> *very private."* (Emma, interview, page2)

A final factor that the carers identified was the attitudes of other professionals.

> "*I know myself that the staff can sometimes not help, they haven't the experience or they don't know how to help a woman who has learning disabilities."* (Janet, interview, page2)

> "*Elaine: [Speaking of a woman with profound LD] There was a letter that came in recently from her doctor saying that he didn't think she should do this.*
> *DW did he give any reasons why?*
> *Elaine: No, he just said it would not be a good idea and this is where we come in."* (Elaine, interview, page2)

Janet had been a breast care nurse and was critical of her peers since working with this client group. Her point reflected the experience of Fergi and Annie and reinforced the need to increase the understanding of the needs of women with LD. With Elaine, the rationale behind this letter from the GP was unclear as the GP had not had contact with this client for some time. Elaine believed that it was up to her team to advocate on her behalf and to explore this further, rather than make a judgement on a letter from the GP.

The key findings from this section were that the support during breast screening needed to be assessed on an individual basis. Reassurance again played a large part in helping the women through breast screening, but mammographers must be attentive to the needs of women with LD and their carers. The findings also revealed that more understanding about the needs of women having breast screening are required. The main barriers identified by the carers were fear, embarrassment, parental attitudes and attitudes of health professionals.

5.4.   Summary

The carers' views presented here indicated a number of problems for women with LD attending breast screening. A fundamental issue was that responsibility for the women's health was confused within the care sector and this was aggravated by parental influences. The women also lacked insight into their health and this was exacerbated by poorly defined health education. In most cases, health information was informal and discussions about breast screening

were initiated on receipt of the formal invitation to attend. A key difficulty was the inability to monitor breast health among the more independent women, in contrast to the more dependent women who were monitored through assistance with personal hygiene. Carers were seen to play a crucial role in supporting women through breast screening and the explanations they gave of the procedure would be instrumental in formulating the women's decision to participate. Reassurance was identified as a primary element in supporting the women through breast screening whilst fear and unfamiliarity of the procedure were seen as deterrents. The women's experience of breast screening could be improved by more awareness of their needs within the mammography service.

Chapter 6:   Findings: The Allied-Professionals

6.1.   Introduction

In this chapter the views of the ten allied-professionals are presented. To recap, all allied-professionals in this study had a health remit. Pat was an advocacy worker who ran a women's health group as part of her role and was the only allied-professional that did not work in the NHS or consider herself 'a health professional'. The other allied-professionals all worked in the NHS and had trained for a specific profession: community LD nurse, practice nurse, mammographer, or speech and language therapist. A minority of allied-professionals (Mara, Carol and Clare) only had occasional contact with people with LD whilst the rest worked specifically with people with LD and had a mean length of experience of 18 years[6] (range 3-23 years).

The views of the allied-professionals are drawn together under two themes. The first, '*Talking about breast health'*, explored the allied-professionals involvement in ensuring the women kept their breasts healthy and was divided into three sub-themes. '*Discussing breast awa*reness' identified where the women obtained their knowledge about health and breast health, and presented some of the problems of discussing breast awareness with the women. The second sub-theme, '*Discussing breast screening,*' identified the difficulties of explaining what this entailed and the taboos around the breast in older women. The final sub-theme, '*Barriers to breast screening'*, identified reasons for not attending breast screening which centred on the way breast screening was organised. The first two sub-themes followed the main topic guides within the interview that asked about breast awareness and breast screening and are supported by data from observations and field-notes. The third sub-theme emerged from the discussions within the interviews, observations and field-notes. The second theme, *'Perceptions of others'*, identified how the allied-professionals perceived their colleagues and paid-carers. The sub-theme '*Breaking down the barriers'*, explored a need for more interdisciplinary working

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[6] One participant declined to give details

while '*Carers'* explored the concerns the allied-professionals raised about the care sector. The first sub-theme reflected the opening question of the interview while the second was drawn from material throughout the interview.

6.2.   Talking about breast health

This theme explored the allied-professionals involvement in ensuring the women kept their breasts healthy. The theme was expanded upon through the three sub-themes.

6.2.1.   Discussing breast awareness

This sub-theme explored how the allied-professional discussed the issue of health and breast awareness with the women, including where they obtained information, how the information was put over to them and the terms the allied-professionals would use.

The allied-professionals were asked how women with LD kept themselves healthy and echoed the views of the carers by acknowledging that the women were not good at keeping themselves healthy.

> *"They [women with LD] are generally unfit and*
> *unhealthy and it's a real problem with them."*
> (Rita, interview, page3)
>
> *"They are a group who are very vulnerable at*
> *times about their health because they don't*
> *necessarily recognise [or] understand the*
> *problems."* (Jo, interview, page6)
>
> *"The person isn't going to know about or think*
> *about it themselves someone else has to do it on*
> *their behalf."* (Pat, interview, page4)

Pat identified that the women often needed the help of others. David, along with six other allied-professionals, suggested that having someone helping with personal care meant that they could monitor changes.

> *"If they require assistance with personal care, they probably are the group that is less likely to be missed because someone else is keeping an eye out for changes but for those who live alone it's a problem."* (David, interview, page5)

This reinforced the views of some of the paid-carers that the more dependent women would be better monitored for health problems. This led on to a question about where they thought the women obtained their knowledge about health, especially breast awareness and breast screening.

> *"I suppose they get some from here [Health centre], but also family and carers."* (Clare, interview, page2)

Clare's response typified the replies, although television soap operas were also identified by four of the allied-professionals.

> "*Soap operas and television has a large part to play as our clients watch that and take it very seriously."* (Joyce, interview, page4)

> *"Soaps are a godsend 'cause it makes people sort of ask questions if they have seen it on the telly."* (Clary, interview, page4)

This reflected the views of the carers. Soap operas were seen as a medium for conveying health messages since they could open up dialogue with these women to discuss these issues. As with the carers, allied-professionals confirmed that the women had few friends.

> *"They don't really have a network of friends, it's usually other carers."* (Clary, interview, page7)

> *"Staff are often seen as friends and they don't seem to be able to differentiate between staff and friends.*" (Rita, interview, page5)

Rita's identification of the difficulties the women had in differentiating between friends and staff suggested that not only were carers a means of support but also a source of influence.

During discussions in the interview about where the women obtained their knowledge, six allied-professionals identified a divide between the younger and older female LD population.

"Some of the younger women may get it from college, school and that but the older women definitely from us." (Rita, interview, page2)

"There is more health promotion in special schools than there used to be, but for these ladies it was missed out." (Carol, interview, page4)

Generally, the view of the allied-professionals was that health professionals were the main sources of information for older women. Health was now incorporated into the school curriculum for all children. The older women would not have benefited from this change so they would be less aware about the need to check their breasts or wider health issues. Opportunities had to be identified by the allied-professionals to discuss breast awareness with the older women. It was observed that Ronnie had earmarked time during her visit to check Pippa's weight to broach breast awareness because she knew she was due to go to breast screening soon.

"After checking Pippa's weight and discussing the problems of being overweight she moved onto breast awareness. Ronnie started by asking whether she knew why she should check her breasts Pippa said she didn't know so Ronnie explained." (Ronnie, Observation1, page1)

"Can you remember what we said about checking your breasts last time? Pippa was hesitant but said she could. There was silence. Ronnie asked her 'what do you check them for' there was a pause, 'you check them for lumps'. Ronnie praised her." (Ronnie, Observation2, page1)

Talking about breast awareness with the women (and in some cases with carers) was something that the allied-professionals regularly undertook, with the exception of David, Jo, Joyce and Pat. David always referred his clients on to a female colleague, although would talk to the woman initially about it. Jo and Joyce were both Speech and Language Therapists who worked with colleagues in their respective community LD teams. Although they took part in workshops on breast awareness, this tended to be undertaken jointly with the CLDN. Pat only broached the subject periodically as she had a wider remit than just health. When talking about breast awareness, the allied-professionals identified a number of generic issues about giving information to the women.

> *"Recognising the limitation this person has in terms of understanding."* (Jo, interview, page6)

> "*When you think you are getting the message across someone comes back and makes you realise they haven't picked up on it."* (David, interview, page4)

> "*I would probably explain to them as I would any other woman but I would but tailor the language to below that of a normal woman who does not have learning disabilities."* (Clare, interview, page3)

The issues identified by the allied-professionals centred on comprehension and tailoring language. These issues reflected the findings on the carers. Although Clare rarely worked with women with LD she was aware of the need to tailor her explanation to the woman's level of disability. The types of phrases and words used by the allied-professionals varied, although lumps and bumps were terms all the allied-professionals used most.

> "I would explain you need to feel for lumps and bumps."
> (*Rita, interview, page 3*)

> "*Clary asked Wendy, have you checked your breasts for any lumps and bumps recently? Wendy said she had and she'd found nothing and then said 'she wasn't going for breast screening, no way'."* (Clary, Observation1, page1)

The allied-professionals said that if one of their clients used the term cancer then that would be term they would use rather than lumps and bumps. When explaining how they would explain breast awareness to the women, the decision to use the word 'cancer' was found to be an individual one. Some like Carol believed the women needed to have detail while others like Joyce would be honest but tailor this to the individual woman.

> *"Cancer depends on the person what they understand. You don't want to frighten them but they do have to have some explanation."* (Carol, interview, page2)

> *"It would be dependent on the individual and their comprehension but we tend to be as up front and honest as we can."* (Joyce, interview, page4)

Again cancer was associated with fear. These explanations also reflected those of the carers. In addition to a verbal explanation the allied-professionals would also employ booklets. This was no different to some of the carers. The publications of choice were the FAIR booklets because these were produced by a local organisation. Furthermore, six allied-professionals in this study had been involved in piloting or writing them.

> *"We have an awful lot of good leaflets out there, sort of FAIR which we helped produce and we work collaboratively with them so really the pitch would depend on their ability level."* (David, interview, page1)

Two of the allied-professionals who had been involved in writing the leaflets also acknowledged that they were not useful for all clients.

> "*Fair's leaflets are great but they are often not in-depth enough or still not simplistic enough for a lot of our clients."* (Joyce, interview, page1)

This was an important point that was rarely voiced within the literature. All the allied-professionals acknowledged that whilst the leaflets were extremely useful, they needed to be used in-conjunction with the help of carers or allied-professionals.

> *"I think the leaflets are good but I don't think*
> *they are good on their own because people*
> *always need someone to go through them with*
> *[them]."*(Pat, interview, page4)

This posed another problem. The booklets were useful, because the women could take them home, but reinforcing the messages within them was dependent upon the support the women received.

During the interviews the allied-professionals were asked whether they thought there was enough information for women with LD on breast screening, breast awareness and health generally. They all thought there was, although four indicated that these resources were not used to their full potential. For example:

> "*We have this big folder of stuff on the shelves*
> *and I knew it was there but I have never looked at*
> *it before. We need to make more use of what we*
> *have."* (Clare, interview, page3)

She had been given the cervical screening kit produced by the Healthy Women's Group, but although she had clients with LD who attended for cervical screening, she had never read the material or used it. Mara and Carol were producing an in-house DVD about breast screening for women with LD and they raised the problem of disseminating the information to the right people.

> *"It's getting the information out there as maybe*
> *carers don't know about this*." (Mara, interview,
> page3)

This was supported by my field-notes, since many of the paid-carers were not always aware of the resources produced by FAIR and other organisations or how to obtain them.

> *"Emma said she knew there was information on discussing breast awareness. I asked her whether she seen the FAIR booklets she said she had but didn't know how to get hold of them."* (Emma, field-notes, page1)

This raised an important issue about disseminating materials to carers and the women. Within the discussions on how the women kept their breasts healthy, ascertaining whether the women checked their breasts was problematic.

> *"A lot of our clients say what you know you want to hear but whether they are carrying it out [breast checks] is where the difficulty lies."* (Clary, interview, page1)

Five allied-professionals raised this point and because of the difficulty in determining whether the women checked their breast they broached the topic on a regular basis. They believed that this reinforced the need to check their breasts. To help the women understand the importance they also gave advice to the carers. This followed the guidance given by the NHS Breast Screening Programme, which suggested observing the breast rather than palpating it. If anything unusual was detected carers were advised to check it out at the GP or local breast unit.

> *"We would be asking carer and parents just to be observant while they are supporting people with their showering during personal hygiene. Any concerns should be reported."* (Carol, interview, page2)

> *"The other issue for carers is the awareness to check their own breasts but there are issues about doing [this] for someone [else] and ... carers don't want to over step a boundary they feel uncomfortable with.*" (Jo, interview, page2)

Touching the breast was not advised for carers, only for the individual woman. There were clear boundary issues about doing this given the potential for accusations of sexual abuse.

In summary, talking about breast awareness in women with LD was complicated, because of the women's ability to comprehend material varied. A key message was that leaflets were not always sufficiently simple or detailed enough for the women and knowing how to access them was problematic. As with the carers, there was found to be no consistent source where women with LD obtained their knowledge on breast health. For younger women the school curriculum was playing a bigger part in this, but this remained a difficulty for older women.

6.2.2.   Discussing breast screening

This sub-theme explored how the allied-professionals approached breast screening with the women. The sub-theme encapsulated the questions posed around breast screening. To add some context, the allied-professionals were asked whether or not they had undergone breast screening. Only one of the ten allied-professionals had done so, although only three were eligible at the time of the interview.

When asked what their views were on the argument of some researchers that women with LD should not participate in breast screening, unsurprisingly all allied-professionals strongly believed the women should participate. This opened up a discussion on supporting the women through breast screening. When asked whether they had discussed breast screening with the women, eight replied that they had. Examples of how this was described are given below.

> *"I would just explain that they take a picture of your breasts and they can see kinda through it and see if there is something inside that might look like cancer."* (Pat, interview, page1)

> *"We tell them we are going to take an x-ray and that it might be uncomfortable."* (Mara, interview, page1)

> "*I would explain that it's getting a picture taken an x-ray but then for some clients they may not have had an x-ray.*" (Rita, interview, page2)

Four allied-professionals used the analogy of an x-ray to describe breast screening. However, as Rita suggested, this was not always a useful description because some women would have no experience of this. As with the carers, few allied-professionals made reference to the pain of the procedure. Mara (above) suggested that it would be uncomfortable whilst Clary spoke about 'getting her boobs squashed'. Yet pain was something the women had openly commented on in the study.

Only two allied-professionals (Pat and Ronnie) mentioned about what would happen if something was found on the mammogram.

> "*...also being aware that if there is anything the consequences, that you then have to go to hospital and that.*" (Ronnie, interview, page2)

Carol (a mammographer) suggested the need to be explicit with the women about what to expect. She also explained to the women that they would feel vulnerable by being naked.

> "*You need to give details such as you need to slip your top off and strip down to skin and be exposed.*" (Carol, interview, page1)

Within the interviews five allied-professionals suggested that for the older women this was a taboo area.

> "*With a chest x-ray you can say you are going to stand in front of a special machine those are the things they know how to do ... breast screening it's not, it's taboo you have all sorts of people touching you when they are perhaps not meant to touch.*" (Joyce, interview, page2)

"You don't look, you don't touch, don't poke it's nothing to do with you, cover it up and don't let anyone see. That has been ingrained into so many people. It's slightly different with the age group coming up but the generation that are out there now that was what they were told." (Ronnie, interview, page1)

Joyce referred to touching as taboo because the older women were not used to being touched in areas such as the breast area either by others or themselves. For many women this reflected their institutional upbringing which was often repressive in sexual matters. This was reinforced through an anecdote in my field-notes.

"*Veronica told me that many of the clients came from [Rosecottage]. It was run by nuns and the men and women rarely mixed. If a woman sat on the same chair as a man had sat on they used to put newspaper on the seat before she sat down to stop her getting pregnant. She said 'you can imagine the lack of knowledge this generation of women had'.*"
(Veronica, field-notes, page2)

This clearly demonstrated why some older women might have difficulty in attending breast and cervical screening. It also helped to explain the reasons for their lack of knowledge about sexual health matters. Moreover, given that cervical and breast screening were only established in the 1980s, many of the older generation of women with LD may not have received invitations to attend screening and so would not have habituated to incorporating this into their pattern of life.

"The older women, it's harder as they're not used to all these tests and undressing. We have to perhaps do more for this group." (Mara, interview, page2)

"Women's health is very invasive there's always an aspect of disrobing and showing your private parts to someone strange. I don't think this has really been considered." (Rita, interview, page5)

The issue of undressing was also an issue I had raised in my field-notes after Rita's interview. The issues identified here were important for understanding the current generation of older women and suggested that their experiences needed to be factored into breast screening.

> *"Rita had mentioned that women's health seems to always involve an aspect of 'disrobing' 'showing private parts to strangers'. This tied in with what the others had said about the older women and the issues of boundaries. ?is Rita correct – has this been overlooked in this group of women by the literature."* (Rita, field-notes, page2)

One of the most innovative ways to help women with LD understand breast screening was described by David.

> *"In one particular situation it was down to very creative carers who were due to go for their mammogram at the same time and just thought if I go first they go after and that's worked. But that is people volunteering to put themselves forward for that role."* (David, interview, page2)

This would not be appropriate for all women and not all carers would be comfortable with doing this. This again raised questions about the boundaries and ethics of this, as it might have put undue pressure on the women who watched to have their mammogram. Another interpretation was that it demonstrated the extent to which some carers would go to help the women understand and access breast screening.

The allied-professionals were asked whether they had accompanied a woman through breast screening. Excluding the mammographers, Rita and Clary who were both CLDNs were the only allied-professionals that had. This was unsurprising as the allied-professionals generally saw this as the prerogative of the paid-carers.

> *"It would really be the support workers to support them through that. Unless it was a lady who lived on her own but if there were support workers there we'd be asking them to support her."* (Ronnie, interview, page4)

The women Rita and Clary had accompanied had both been for mammograms before and were very independent hence neither nurse accompanied the woman into the x-ray room. This perhaps explained their lack of details about supporting them.

> *"It wasn't my client [but] I chummed her to have a mammogram. She coped with it really well, the staff were excellent. My colleague had fully prepped her, she knew exactly what she was going for and this was her third screening so it was fairly straight forward for her."* (Clary, interview, page3)

> *"She had been recalled and already had the information given to her, I was just following up her letter ... I suggested that she went to the mobile unit because it's five minutes from where she lives. They [mammographers] were excellent, really good with her."* (Rita, interview, page1)

What was important here was that both women had been fully prepared and were familiar with the procedure. Clare also identified that being familiar with the procedure and 'staff' were important facilitators:

> *"If they are regular attenders, they might get to know people and that might break down barriers as well [such as] coming to a strange place meeting strange people and so on."* (Clare, interview, page4)

In addition the mammographers were praised for the way they dealt with the women. When I observed the two mammographers, there were no women with LD but I shadowed one woman, Julia and observed her having several procedures.

> *"Mara led Julia into the room for the mammogram. She asked if she'd had the result of this first mammogram. Julia said she'd been asked to wait as she needed another one. Mara said that this sometimes happened and that they would take two pictures of each breast again but this time it got in closer to check the shadow. She said that she may feel some discomfort again but that this was normal and wouldn't last long. She also said she might need to manoeuvre into place and to let her know if she had any mobility problems."* (Mara, Observation1, page1)

This piece of observation contrasted sharply with the experience of Fergi. Mara explained clearly what she was going to do and what she should expect. Within this she tried to reassure Julia by saying that she needed a close look and that this sometimes happened.

In summary, the key finding from this section was the difficulty in explaining what breast screening entailed. This was because experience of x-rays was not universally understood by all the women. The findings also highlighted the limited references to pain of the procedure or potential follow-up if a lump during the explanations about breast screening offered to the women. An urgent issue requiring address was the lack of health education among older women and their perception of the breast as a taboo area. In contrast to the views of the women and carers, the professionalism of the mammographers in supporting women through mammography was noted. This suggested there were pockets of good and poor practice within this service.

6.2.3. Barriers to breast screening

This sub-theme explored the barriers to breast screening and emerged from the discussions about breast screening within the interview. The allied-professionals also suggested ways of improving and enhancing the experience for women with LD.

The allied-professionals identified a number of obstacles. One was the effect of past negative encounters during a hospital appointment.

> "*There is often the fear factor as some of our clients have experienced lots of appointments for lots of different things and lots of them may not have been pleasant.*" (Jo, interview, page2)

Jo identified the reason for some women being fearful of going for health appointments. Sometimes this is exacerbated by poor communication by healthcare staff as Clary suggested.

> "*He didn't explain it to her so he put the needle right in [her breast] and after that experience she said 'I ain't going back again'.*" (Clary, interview, page3)

This woman needed a painful breast cyst drained but understandably after this experience was nervous of returning. Whereas women in the general population would be able to rationalise the reason for having to go back, Clary's client was clear that this was not going to happen. This again demonstrated the binary thinking of some women with LD. The episode highlights how health professionals who are not used to working with this client group need to be aware of the consequences of their actions for people with LD. For some women, even the most routine appointment caused trauma.

> "*I have quite a lot of clients who find the dentist very difficult and who need sedation before they go ... and that whole process is quite complex ... so the thought of another appointment that isn't necessary in people's eyes is probably off-putting.*" (Jo, interview, page2)

Jo clearly described the complexity involved in attending the dentist for some clients and through this gave an insight into why some appointments, such as breast screening, were not prioritised. Although her reference to sedation for the dentist may have seemed extreme, this was often the only option for some women if the treatment was needed. As identified by the carers, sanctioning of sedation would usually require a risk assessment and discussions with those who supported the woman. Another barrier identified by all the allied-professionals through the course of the interviews was the influence that carers had on the women.

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> "*They are influenced by those who are providing*
> *care, 'och dinnae bother with that, I haven't'."*
> (David, interview, page6)

> "*Elderly parents aren't aware or a little afraid of*
> *things themselves or have gone for a screen and*
> *had a bad experience and with the best will in the*
> *world don't want to put their child through that."*
> (Joyce, interview, page3)

The allied-professionals thus identified carers as being influential in dissuading the women from attending breast screening based on their own experience and or lack of understanding. Joyce raised the point that sometimes parents tried to protect their daughters from having a poor experience. The use of the term 'child; is interesting, since these women would be fifty years of age or older. This comment also provides insight into how the allied-professionals viewed relationships between parents and their adult off-spring. This was reinforced when four allied-professionals described some of the problems they had experienced when raising the issues of screening with parents and carers.

> "*The difficulty with parents and carers is they*
> *don't see them as sexual beings.... 'so let's not*
> *even talk about that' .... I mean it's a no-go*
> *area."* (Clary, interview, page4)

Women's cancer screening was frequently associated with sexual areas and this was considered a taboo subject. For some carers this was a difficult boundary to cross. Ronnie also suggested that some women with LD never had the opportunity to decide about attending breast screening because their parents or carers made the decision on their behalf.

> "*Some are still living with an 80 or 90 year old*
> *mother and 'no she doesn't need it'...so she*
> *doesn't even get the chance to go as they read all*
> *the letters."* (Ronnie, interview, page6)

Both the paid-carers and allied-professionals in this study had criticised parents of women with LD for not allowing their off-spring to attend screening. In this study the family-carers had few issues over breast screening, although Vicki unlike the others had reservations over her daughter going for cervical

screening. In contrast to Ronnie's assumption, many women with LD made their own decisions.

> *"She made it quite clear that she is never going to have a mammogram ... and it's tough [but] you have to stand back."* (Clary, interview, page4)

> *"Once they make a decision and say they don't want to go for breast screens, we can't then say 'well come on you're going'. You have to respect that decision even if you don't agree with it."*
> (Rita, interview, page4)

In these examples the allied-professionals respected the decision of the women even if this went against their professional judgement. This emphasised the dilemma the allied-professionals often encountered in their work. In these circumstances the allied-professionals had to use their professional judgement to protect the rights of the women.

> *"I don't listen to carers telling me I have to do it. If I don't feel it's what the woman wants and it's not acceptable to her then I stop. I won't let anyone tell me I have to carry on."* (Carol, interview, page3)

Here Carol suggested she would take the woman's wishes into account and observe her behaviour before complying with the carer's wishes. This scenario also sheds light on the difficulties encountered within the health sector about consent. Seven allied-professionals raised concerns over informed consent. For example:

> "*There's still a lack of awareness of people's understanding and people are over-estimating and assuming that when someone agrees to something that they are giving fully informed consent and that often isn't the case.*" (Jo, interview, page5)

What concerned the allied-professionals was that people who rarely worked with women with LD were not aware of their tendency to acquiesce to things or

challenge this decision. When interviewing Clare, she questioned her own practice and revealed that she had not fully investigated the understanding in the women with LD that came for their cervical smears. She later revealed that as a result of this discussion she would more vigilant in the area of consent in the future.

> *"The couple that have come in for smears over the last few years have come in alone and I'm assuming that they have got some understanding."* (Clare, interview, page4)

The main barrier to breast screening identified by allied-professionals was the way screening was organised.

> *"The infrastructure isn't there to accommodate our client group as best as we would like."* (David, interview, page5)

The above quote summed up the allied-professionals problems with helping the women access breast screening. The initial problem identified was the arrival of the letter of invitation for breast screening.

> *"They're sent a letter centrally and we say we will be x-raying them and this helps to see if you have a lump or cancer."* (Mara, interview, page1)

Although there were adapted letters of invitation for women with LD, not all the women received them. Even with an adapted letter many women with LD would still be unable to read it.

> *"If they get a standard letter of appointment and it's something that they have never experienced before their literacy skills are often fairly poor and that also may be true of their carers."* (Jo, interview, page3)

> *"I know two women with LD and I don't know if they are literate or not. They might have to have their letters read to them."* (Clare, interview, page3)

Jo identified that the paid-carers might have literacy problems. This was important as this might influence the women's decision to attend. All the allied-professionals acknowledged that most women would not understand the invitation and suggested this as a reason for non-attendance. This was less likely in group housing where care was twenty-four hours as the paid-carers would generally intercept the mail. As with the carers, this was identified as more problematic for those women who lived alone with minimal support. Four allied-professionals suggested that alongside this factor there was the problem of ill health.

> "*The problem is that when things come in it may not be the best time to receive an invite. They may be having a mental health blip when they are offered it.*" (Rita, interview, page4)

People with LD often had competing health issues and appointments. For this reason breast screening would often not be seen as a priority. Knowing when the invitations had been sent out and who had a disability was an area that all allied-professionals thought could be improved. This was important for the mammographers because they were not always informed that the next woman to be screened had an LD.

> "*Physically you never know who's coming through the door ... so it can be blind, deaf or other physical disabilities and we have to cope. It's easier if we do know but we can note it down for next time.*" (Mara, interview, page1)

Mara raised an important issue in that the mammographers would be better prepared if they knew in advance who had a disability. For this reason an in-house record had been devised. One reason this was important was because breast screening was arranged on a time-limited appointment system.

> "*The problem is the time. It's six minutes per person.*" (Mara, interview, page2)

> "*You need to give a lot of reassurance and that's important, but again you battle with time.*" (Carol, interview, page3)

As Mara explained, appointments were limited to six minutes per person and if the woman had difficulties, then the mammographer had to try and make up time to prevent the next person having to waiting longer. This was demonstrated in the observation with Carol.

> *"Carol apologised to Julia for the wait, and explained that there had been a problem with the last lady. She showed us into the room and told Julia to take her blouse off, (Julia had undone it and was being rushed to the machine, her breasts were exposed and her blouse open this seemed undignified). She explained that she would have a mammogram and then Dr Wilson would ask her some questions. Carol manoeuvred her into position. Seemed flustered."* (Observation1, Carol, page2)

Carol's appointments were running behind by ten minutes. My interpretation of this interaction was that it was very rushed and the dignity of the patient was compromised. I was unable to speak to Julia afterwards as she had just been told she had cancer and I believed that this would have been inappropriate. In the interview, Carol spoke about the problem of time and acknowledged that you had to give a lot of reassurance. However, as the observation demonstrated, this was often difficult because of the system they worked within. This type of experience might have had a negative impact on future visits for some women. For women with LD, this had implications for meeting their needs as they may require more time and support. This was something that Jane (woman with LD) spoke about earlier.

For those who worked with women with LD regularly, if they knew who had been invited for breast screening they could begin preparing the women for breast screening.

> *"We can show them round and give them information and make a double appointments. There has to be some way of knowing who needs an appropriate letter and extra time and so on."* (Rita, interview, page2)

> *"How can you plan, prepare and set up services,*
> *when you don't actually know how many people*
> *you are dealing with."* (Ronnie, interview, page5)

Rita identified some of the support she could offer the women but in order to give this type of support she had to know who had been invited. This was similar to Ronnie who raised the issue about service planning, as it might have been easier and more economical to run a group than see clients individually. To do this you would need to know who had been invited for breast screening. A solution would be to share data but Mara identified problems with this.

> *"We try and liaise with GPs, but then there are*
> *ethical issues about information sharing."* (Mara,
> interview, page2)

To share data, each individual would need to consent to this. This raised issues for people with LD about capacity and consent. What the allied-professionals identified was that the present system of offering women opportunities to attend breast screening often left little time to prepare the women. To counteract such problems, five allied-professionals suggested having more flexibility within the system and to allow the women to try again if their first trip to breast screening failed.

> *"If we've done the best we can and if it doesn't*
> *work then they should have the opportunity to try*
> *again. I can appreciate that clinics have a lot of*
> *people to see but I would like to think they would*
> *say we'll give it a go again six months down the*
> *line."* (Joyce, interview, page2)

This would be the ideal situation for those women with LD who found it difficult. However, it may incur additional resources, such as staff costs due to additional input from allied-professionals as well as a paid-carer's time to accompany the woman.

To summarise: the allied-professionals identified a number of barriers that prevented the women from attending breast screening. Decisions about attending were seen to be influenced by previous experiences at health

appointments and the knowledge and attitudes of the people who supported them. A major problem identified was the way breast screening was organised as it did not accommodate women with LD. This was compounded by a standardised invitation procedure which did not take account of poor literacy skills and the need to work within a constrained appointment system. Being able to identify who needed additional support was welcomed by those who supported the women and those who performed the mammogram.

6.3.   Perceptions of others

This theme encapsulated the views about other professionals and carers whom the allied-professionals worked with. It was drawn together under two sub-themes. '*Breaking down the barriers'* identified the concerns of those who specifically worked with people with LD and the need for interdisciplinary working. The second sub-theme, 'C*arers*,' explored the concerns the allied-professionals raised about the care sector. The first sub-theme reflected the opening question of the interview whilst the second was drawn from material throughout the interview.

6.3.1.   Breaking down the barriers

This sub-theme explored differences within the roles and attitudes towards people who worked with women with LD and those who did not. All the allied-professionals worked on a referral basis. This meant that all the clients whom the allied-professionals saw and worked with had to be referred to them by another professional such as a GP. Those who worked exclusively with people with LD expressed concerns about the referral system.

> "*I would say the vast majority of people with learning disabilities out there aren't tapping into our service so how do we stop them from slipping through the net.*" (David, interview, page7)

> "*The problem is we don't see everyone with a learning disability so we only can help the ones we know about.*" (Rita, interview, page3)

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These concerns arose because these allied-professionals understood that people with LD often had limited knowledge about how to maintain their health or access health services. This was compounded by the lack of knowledge about the health needs of people with LD in other professionals and lay people.

> "*There is often a misconception that our clients*
> *don't suffer the same illness that the rest of us do*
> *so I think there's a barrier in terms of getting them*
> *through the door.*" (Jo, interview, page2)

This concern stemmed from the awareness that some emerging health problems were merely seen as part of the trajectory of having a LD, rather than a cause for concern in those who supported the people with LD. Furthermore, few allied-professionals working outside the LD field would understand or have the skills to manage the challenging behaviour or communication problems inherent in this client group.

> "*We have still not broken down the barrier that*
> *they'll be a nuisance, they'll be a challenge,*
> *they'll be not wanting to take part, they'll be*
> *behaviour problems and it's easier if we just don't*
> *bother.*" (Ronnie, interview, page5)

The concerns identified by those who worked regularly with people with LD were based on the assumption that if people with LD presented with challenging behaviour they would not receive the necessary treatment. Although this suggested some hostility towards professionals outside the LD field, many wanted to raise awareness about their clients to help others understand the challenges people with LD faced.

This was particularly important because people with LD need specialist services.

> *"It's about us promoting and supporting other services rather than ghettoising the health care of the people we work with. I think there is a risk that people go 'oooo there is a learning disability team and this person has a learning disability and there you go'. Clearly we can't be expert in everything and clearly we are not."* (Joyce, interview, page4)

What Joyce was suggesting was that people with LD were not confined to their own speciality i.e. 'learning disability' and someone from, for example, a cardiology speciality needed to develop skills in learning disability. What she believed should happen was interdisciplinary working, for other specialists to work with the learning disability team. There was some movement towards this through the liaison nurses service. The liaison nurse had a specific remit to help prepare people with LD for their time in hospital and support the staff that would be looking after them.

> "*We have got a great resource in a liaison nurse they can help us prepare on both sides, prepare the clinics and prepare the medics to understand what this person needs and why this person needs this.*" (Jo, interview, page5)

This suggested that some headway was being made in working with the ward staff and clients to enhance their hospital experience.

In summary, those who rarely worked with people with LD were perceived by those who worked specially with people with LD to have a number of misconceptions about the health needs of people with LD. This had fostered a need for better interdisciplinary working to ensure people with LD received the best possible treatment.

6.3.2. Carers

This sub-theme denoted the pivotal role that paid and family-carers played in checking, monitoring and supporting people with LD about their health. It also identified the allied-professionals' concerns about this group. All the allied-professionals indicated that carers were central to supporting the women with

their health needs, but six voiced concerns about carers' lack of knowledge in health matters.

> *"The onus is really on the support staff but their knowledge and understanding is often quite limited."* (Mara, interview, page3)

> *"Carers don't know what they should be looking for in their own health much less somebody else's."* (Jo, interview, page3)

Although these views contrasted sharply with the care given and the knowledge demonstrated by the paid-carers in this study, the issues raised were important because they identified a tension between carers and professionals. However, 'health' was only one aspect of the paid-carers role. A particular health concern identified by half the allied-professionals was obesity.

> *"The big one at the moment is obesity. We're treating people like fat geese out there, we're pumping food down their necks, you have paid-carers who have no understanding of diet and they bring their own value base to work."* (David, interview, page6)

> *"People had poor diets and were not supported to make choices or understand the consequences with your health and now you see people who are overweight."* (Pat, interview, page2)

The problem of the women's obesity was suggested to stem from the poor knowledge of the paid-carers. Although educating the people that supported the women was one solution, this was compounded by the high turnover of staff within the care sector.

> *"They maybe know someone for a couple of months and then they go and then someone else comes. So you never actually build up a good relationship with someone ... but that's the nature of the employment, no-one stays very long."* (Ronnie, interview, page6)

> "*There's such a high turnover of voluntary sector carers and managers and staffing amongst that sector.*" (David, interview, page9)

Ronnie identified that high staff turnover meant little continuity of care. Consequently, monitoring subtle changes in the women's breasts or general health status would be problematic. The problem of staff turnover was also reflected in the views of the carers themselves. However, it was inevitable that people in low-paid roles would seek different employment. Four allied-professionals also criticised the lack of continuity of GPs.

> "*The GPs up until recently knew really knew nothing about her so there isn't a name you can identify with.*" (Clary, interview, page3)

Having a named GP meant that there was a stable point of contact for both the allied-professional and also their client. Rapport could be therefore built up which was regarded as important if the needs of that person were complex and there were on-going problems that required specialist services.

To summarise, the allied-professionals believed that carers were essential to help maintain the health of people with LD. However, a problem within the care sector was the high turnover of staff which negatively impacted on continuity of care.

6.4.   Summary

A key finding of the views presented was the deficit in older women's health knowledge, especially as these were the women who were now eligible for breast screening. Reasons for this deficit varied from lack of provision for health education, poor knowledge in the paid-carers and the belief that 'breasts' were a taboo subject. This was not seen as problem for the current generation of younger women because their health education commenced at school. Another issue was the lack of communication about who was attending or had been invited for breast screening. The Community LD teams were restricted to the women on their caseload due to the referral system they worked within.

Hence not all the women would be known to them and this had consequences for the more independent women because no-one was checking up on them. Discussing health matters was seen to involve generic issues, such as difficulty in knowing what was being comprehended.

The experience of breast screening suggested that here were pockets of good and poor practice within the screening centre. Invitations were sent out centrally and did not always accommodate the literacy problems within this population. The experience of having a mammogram was constrained by the six-minute appointment and the unfamiliarity of the procedure. Being able to identify who needed additional support was welcomed by those who supported the women and those who performed the mammograms. To facilitate a better breast screening experience, more interdisciplinary working was needed to raise awareness about the needs of these women.

Chapter 7:   Cross-analysis and Discussion

7.1.   Introduction

This chapter discusses the key findings from the study. Firstly, the views of the women, carers and allied-professionals in the preceding chapters are brought together and synthesised using the method of cross-analysis described in Chapter three (see section 3.6.7). Undertaking the cross-analysis enabled my representations, interpretations and understanding of the central message about the experience of breast screening for women with LD to be heard and helped to identify what factors influenced them to have a mammogram. Three subthemes, developed from the cross-analysis, were used to assist in structuring the discussion of the findings. These are summarised by a heuristic diagram, (Figure 5). These findings and the synthesis of ideas are then discussed in relation to key literature. The discussion of findings from the women, carers and allied-professionals are discussed under six headings: *general considerations* (which addresses the level of the woman's LD and who had responsibility for her health), *risks of breast cancer, breast awareness, preparing for breast screening*, *attending for breast screening* and *the experience of having a mammogram.*

A critical narrative process about undergoing breast screening is employed (Hammersley and Atkinson 2007). I judged that this approach captured the elements of the diagram in that it told the story from start to finish. New knowledge emerging from the study is identified as well as the strengths and weaknesses of this analysis. Finally, some reflections on the overall research project are offered.

7.2.   Cross analysis

In the following subsections the views of the women, carers and allied-professionals are presented under the overarching theme *'Negotiating breast screening within the current service provision for women with LD'.* This theme suggested elements within the provision of the breast screening as well as

external influences impacted on how women with LD accessed the procedure. Within this overarching theme, three subthemes: '*Cultural perspectives'*, '*Getting them through the door'* and '*Going for a breast screening test'* also emerged which assist in analysing the theme further*.* These themes are explained below.

7.2.1. Cultural perspectives

Undertaking the cross-analysis enabled the cultures of the women, carers and professionals to be synthesised and compared. The subtheme '*Cultural perspectives'* acknowledged that there were different cultures associated with the three groups. Interaction between these cultures had the potential to influence the women's decision about going to breast screening and their experience of the mammogram. It is worth summarising the essential details of each group before identifying the similarities that were found within the cultures when the cross-analysis was undertaken.

Analysis of the culture of women with LD identified that the women needed some support with their health because of their limited insight into their own situation. A critical aspect was that the level of LD dictated how much support the women needed. Some women, for example those with mild LD, were less dependent on carers and although were better able to understand and retain information, had less monitoring of their health. There were also differences between the younger and older women: the former were seen as being better educated about their health than the older generation. Taboos about exposing their breasts and the suggestion that the older generation of women were not used to screening were also identified by those who supported them. Many women had a polarised thought process (i.e. thought in terms of 'painful' or 'not painful') and were unable to understand the benefits of procedures that were painful. In contrast to women in the general population, women with LD in this study were viewed as being very isolated with few friends outside the home (or staff) with whom to discuss issues such as breast screening.

The culture of carers highlighted that the role of the paid-carer was seen as low status and had a high turnover of staff. Paid-carers were also divided into residential and day-care workers: the former were the ones who would support the women most of the time. Whether the paid-carer saw looking after the woman's health as being part of their remit depended upon the philosophy of where they worked. For this reason there were mixed views about where the responsibility for the health of the women lay. This was also compounded by whether or not the women's parents were still involved in the woman's care. The role of the family-carer was constantly shifting from carer to family member. Furthermore, the woman's capacity often influenced the family-carer's decision to become a welfare guardian, as this allowed them to influence the woman's care. The family-carers were generally isolated once the women left school (transition) and had less contact with services.

The culture of allied-professionals identified that they had defined roles, usually aligned to the training that they had undertaken e.g. nurse. This meant that they had specialist knowledge within the area in which they practiced. In many respects their roles were as equally 'bounded' as those of the carers. Not all the allied-professionals worked specifically with people with LD and therefore had limited understanding of this client group. Those who worked specifically with people with LD tended to work in community LD teams which operated within a specific catchment area. All allied-professionals worked on a referral system, therefore they only had contact with people who had made appointments to see them or were referred to them by other health professionals. The referral system meant that those who worked specifically with women with LD did not see every woman within their catchment area and this posed a problem for knowing who had been invited to breast screening.

Despite the differences between the cultures of the women, carers and allied-professionals, a number of similar characteristics about breast screening were identified within their respective views. A similarity identified by the participants included acknowledging that there was a set process around breast screening, which included: risk factors, awareness of changes in the breast and preparation in going for breast screening, all of which resulted in the experience

of having a mammogram. All women with LD in this study needed support at some time with their activities and specifically to access services such as breast screening. The women who were more dependent received greater support, such as closer monitoring of their health, because they needed help with personal hygiene and often needed decisions to be made for them. Similarly, the women in this study needed some explanation about breast screening to prepare them for what to expect. The 'responsibility for the women's health' centred on the roles of those who supported them and the cultures in which the carers and allied-professionals operated. However, there was little understanding about the roles each other played in the life of the woman and both carers and allied-professionals made assumptions about what they should be doing. Within the sector in which the paid-carer worked, roles were poorly defined; this included whether health was part of their remit. This was also the case with the roles of the family-carers, who often had to seek legal guardianship to remain involved in their son or daughter's care. This was in contrast to the allied-professionals who had the most clearly defined roles such as a nurse or mammographer. These roles had clearer boundaries but with this came limitations about what they could or could not do.

The organisation (and the roles) in the care sector in which the paid-carer worked meant that the responsibility for the woman's health was unclear. Within the social care sector there was a lack of continuity of care because paid-carers rotated round different houses or because of high staff turnover. This meant that any health problems could be overlooked. The high turnover of staff reflected the low pay for the work undertaken. The role of the family-carer constantly shifted between parent or sibling and carer; their role in the health of the woman depended on them legalising it in the form of a welfare guardian. To compound matters, the referral system that was operating for allied-professionals meant that not everyone with an LD engaged with the services provided. Not all allied-professionals were experienced in supporting people with LD, which posed a problem in terms of GP care as they are the main gatekeepers to healthcare. A further problematic area identified within the findings was that of communication: not only the difficulty in getting the women to understand information but also between the sectors (health, voluntary and social care) and

those who supported the women. In many ways the women, carers and allied-professionals operated separately and there was little interdisciplinary working identified. One exception to this was when a woman required sedation in order to undergo a health procedure such as dental work or cervical screening. This central tenet was important and key to understanding some of the factors that influenced the women's decision to go for breast screening. Alongside these aspects there were barriers and facilitators to breast screening.

7.2.2.   Getting them through the door

The cultures of the women, carers and or allied-professionals were inextricably linked to the factors influencing participation in screening. '*Getting them through the door'* looked at what might deter and what might encourage the woman to go to breast screening. Within the views of the women, carers and allied-professionals, a number of barriers to breast screening were identified. The immediate obstacles identified were the pain of undergoing the procedure and the embarrassment of having to be naked from the waist upwards. These were compounded by being frightened of the procedure because it was a new experience. Attitudes and anxieties that some parents and paid-carers had towards the women going for breast screening, for example whether it was a necessary procedure or because of associations with sexuality, were also an issue. Women who had more complex needs, such as those with severe/profound LD who were more dependent on paid-carers and required decisions to be made for them about their health and social needs, were also seen as having to overcome more barriers.

Other impediments were the 'Taboos about the breast' which referred to the belief that some allied-professionals had about the women's understanding about exposing their breasts and about them being touched. The final obstacle I identified in the cross-analysis was what I interpreted as the 'culture of breast screening', which described the way breast screening was organised. This included the centralised invitation system which was not always geared to ensuring the women received appropriately tailored invitation letters or double

appointments. There was also the lack of inter-disciplinary working; for example, there was little liaison between GPs and community LD nurses.

The facilitators to breast screening included giving support to the woman, such as accompanying her and/or reassuring her during breast screening, or clearly explaining what was involved in having a mammogram in a way that was tailored to her level of LD. As was the case with women from ethnic minorities and physically disabled women, ensuring that the mammographers were aware of the needs of women with LD was also seen as important. Outwith mammography, support involved making sure that the women undertook surveillance of their breasts or that the breasts were monitored by carers during personal care. This also incorporated monitoring of the risk factors associated with breast cancer. The culture, barriers and facilitators all combined to impact on the experience of the mammogram.

7.2.3.   Going for a breast screening test

'Going for a breast screening test' was also linked to the cultures of the women, carers and allied-professionals. This sub-theme identified the actual experiences of the women which were mainly negative. This included descriptions of some of the barriers discussed above, such as embarrassment, fear, pain from the procedure or positioning the limbs and feeling cold. These feelings and experiences were little different to those reported by women in the general population about going for breast screening.

7.2.4.   Crux of the analysis

Having undertaken the cross-analysis, there were a number of consistent factors that emerged from the views of the women, carers and allied-professionals. Some of these represented the necessary and inherent aspects of having a mammogram, such as the procedure for being invited to mammography, the actual process of having a mammogram (standing naked from the waist upwards in front of a machine) and the need for some preparation for the mammogram, such as an explanation about the procedure,

which was necessary to enable the women to understand the process. The crux of the findings from the cross-analysis showed was both how breast screening was carried out and the way the women were prepared for it, as these aspects could vary widely. This was often inextricably linked to the level of the woman's LD and where the responsibility of health for the women was seen to reside – which reflected the way the LD field was organised and the relationships between the different sectors (health, voluntary and social care) operating within it. The findings from the cross-analysis are represented diagramatically (see Figure 5 below) to show the journey and the influences upon women with LD when deciding about participating in breast screening. Figure 5 is heuristic in so far as it gives a tentative insight into the journey of breast screening. The diagram is explained below and then forms the basis of the main discussion of the findings in this thesis.

Figure 5   Heuristic figure to explain the findings

Woman with LD
Carers
Allied-professional

1. Risks of breast cancer

Obesity, smoking Alcohol, diet nulliparity

2. Breast awareness

Remembering to/ having the breast checked Awareness of checking

Woman with LD
Carers
Allied-professional

5. Experience of having a mammogram

Pain fear cold,

embarrassment

Woman with LD
Carers
Allied-professional

Woman with LD
Carers
Allied-professional

4. Attending for breast screening

Mammography staff,
Poor treatment,
Working around the system

3. Preparing for breast screening

Broaching the subject
Tailored information and explanations

Woman with LD
Carers
Allied-professional

Journey

Inequality

Equality

Figure 5 depicts a spiral journey consisting of five stages. Stage one in the top left hand corner of the figure relates to risks of breast cancer whilst stage two, top right-hand corner of the figure, relates to breast awareness. Stage three, in the bottom right-hand corner of the figure, relates to preparing the women for breast screening, whilst stage four, in bottom left-hand corner of the figure, relates to attending for breast screening. In the centre of the diagram is stage five, which relates to the experience of having a mammogram. Within the figure, the satellite boxes represent the stages of the process of going for breast screening which were identified by the women, carers and allied-professionals. Contained within the boxes are examples of some of the key factors that may influence or impact upon the woman's experience of screening, identified from the cross-analysis. Beside each box are the women, carers and allied-professionals. Bold text indicates whether the women, carers or allied-professionals were the 'key players in this part of the journey'. I acknowledge that all players will exert varying degrees of influence as the process develops, but I wanted to indicate the specific impact of the respective players at each stage of the journey to breast screening. That journey can be interrupted at any part, due to the dynamics that affect the individual, within the home or day-time activities or in various the health arenas.

Having briefly explained the structure of Figure 5, a fuller discussion of each component (stage and journey) will be explained within the context of the literature and policy below. The practical and theoretical lessons arising from Figure 5 will also be discussed.

7.3.   Main discussion

In this section each stage of Figure 5 will be discussed in turn and put into the context of both the findings from this study and of the wider literature and health policy. In order to understand Figure 5 and the full implications of these findings, a number of general considerations need first to be addressed.

7.3.1. General considerations

An important factor that was threaded through the views of the participants and was brought out by the cross-analysis related to the woman's level of LD. The way the allied-professionals and carers supported these women was inextricably linked to whether the women were seen as independent or dependent. The women who were more independent (usually women identified as having mild to moderate LD) were more able to live on their own and had more autonomy in their day-to-day life. This meant that there was less control and monitoring of their health and the allied-professionals and carers had to be mindful to balance respect and autonomy against control. The women who were more dependent (usually women identified as having severe to profound LD) were less able to be autonomous, live on their own and often needed assistance with feeding, personal hygiene and choice. Where possible independence was encouraged but in many cases the severity of the LD meant that most decisions were made by the people who supported the woman and in these circumstances more monitoring of health was possible.

Irrespective of the woman's level of LD, the carers and allied-professionals were united in the fact that all the women needed support to keep healthy and access health services. What also emerged was an inconsistency about how health was assured and who was responsible for the women's health. In essence this depended upon who supported the women, the way the LD sector was organised and the relationships between different health, social care and voluntary sectors. For this reason I suggest that this contributes to inequalities and inconsistencies in care for these women, albeit unintentionally. Thus there are health inequalities and the aspiration to place the women at the centre of health policy may not be being fulfilled. What is needed is a review of the social care sector to produce clear guidance about meeting the health needs of people with LD since at present these are considered as being met within the social care sector. This review would mean listening particularly to women with LD in order to understand their specific needs before proceeding to draw up guidelines and then ensuring that there is equality of care through audits of their implementation within the social care sectors.

Paid-carers within this study were in the main seen to be the ones responsible for the overall monitoring of the women's health. It was presumed that paid-carers in the residential setting had this as part of their specific role remit. However, the findings demonstrated that not all residential paid-carers acknowledged this. Those from the social work funded areas believed health was not their responsibility, either within the residential or day centre setting. Therefore the philosophy of the organisation in which the paid-carers worked was an important factor which influenced their beliefs and actions. If paid-carers did not believe that health was part of their job description, the women were potentially vulnerable to undiagnosed health problems. This finding contributes a new dimension to the contention that poorly trained 'carers' misdiagnosed health problems and emphasises the importance of the context in which support and care is given (Janicki *et al. 2*002; McCarthy 2002; Patja *et al.* 2001; Sullivan *et al. 2*003).

Another reason for this division was that the role and responsibilities of the paid-carers were poorly defined. This was complicated by blurred boundaries, as some family-carers also had input into decisions about the women's health: hence who made the decisions about the woman's health was sometimes unclear. A further consideration was the paid-carer's knowledge of health issues and needs of women with LD. This again was specific to each area and individual member of staff, as there were no clear standards in place regarding training in health needs other than mandatory training or if clients presented with specific problems. This supports the notion that paid-carers are poorly trained with regard to the health needs of people with LD (Janicki *et al. 2*002; McCarthy 2002; Patja *et al*. 2001; Sullivan *et al. 2*003). This has implications for future health policy which will need to take account of the role of paid-carers in supporting vulnerable groups to access health care and ensuring that mandatory training is in place for paid-carers to meet the needs of people with LD.

A factor raised within the findings by both the paid-carers and allied-professionals was the lack of 'staff stability' within the social care sector. This meant the continuity of care for the clients was not as good as it could be.

Continuity was important because it built rapport and enabled the paid-carer to 'get to know the client' (McCarthy 2001). This was important for monitoring the woman, especially in terms of identifying subtle changes within her health (Donovan 2002; Singh 1997). This lack of continuity was twofold. First, it was sometimes a consequence of the way duty rotas were devised, in that paid-carers rotated around the different residential homes in the care organisation. This meant that the woman might see one paid-carer for only one day as the paid-carer may then be moved to another house and client the next day and so on. Second, staff turnover was also identified as a problem within the social care sector because the role was not valued and perceived as requiring few skills. Paid-carers often moved out of the social care sector or to another care organization to gain a better salary, thus creating a vicious circle.[7] These findings support previous work on role uncertainty and staff turnover (Davis and Duff 2001; Hatton *et al.* 2010). This lack of continuity in supporting the women and staff turnover illuminates why paid-carers may be inadvertently missing the health needs of people with LD. Given the problems identified here, there is a need for a clearer career progression within the social care sector for individuals who support people with LD. Failing that, it justifies a need for a specialist NHS LD workforce (Gates 2010). This will have consequences for Healthcare Improvement Scotland which is the body that oversees social care workers as it will impact on future regulation of paid-carers.

In contrast to the paid-carers, the roles of the allied-professionals were more clearly organised around their speciality, such as a nurse or mammographer, and for the most part in terms of the clients they worked with, either LD or non-LD. To some extent these roles were equally bounded, since these professionals had to work within a set remit. For example, allied-professionals saw clients on a referral basis. Thus they only saw the people who were on their caseload or had an appointment for a specific problem. For those working exclusively in the area of LD, this caused frustration because they were more aware that many of their clients would not be getting their health needs met if

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[7] Staff turnover is not isolated to paid-carers within the field of LD but can also be seen within other fields such as the elderly.

they were not interacting with their service. My interpretation was that this represented a missed opportunity for those CLDNs to undertake health promotion activities such as breast awareness or to promote breast screening to carers and women with LD which they would have liked to carry out.

The fact that the women with LD had access to the same services (GP) and specialists (e.g. cardiologists) as the rest of the general population demonstrated social inclusion in terms of accessing the same health services as other women in the general population. Some of the allied-professionals identified that many of these specialists and GPs would have little experience of working with women with LD, which would disadvantage these women because the medical staff would not always understand how to work effectively with them or understand their health needs (Ng and Li 2003; Philips *et al.* 2004). This was why some people with LD were 'ghettoised' in that the management of people with LD was seen as the remit of those specialising in LD rather than being incorporated into mainstream health services. It is acknowledged that practitioners cannot be 'expert in everything' but this again strengthened the need for collaboration and joint working with practitioners who had specialised in certain areas of medicine such as cardiology (treatment of the heart). This would enable a more integrated health service that responded to the health needs of people with LD as well as those of the general population (Tuffery-Wijne *et al.* 2009). The findings also identified a need for practitioners who were not used to working with this client group to be supported, which adds a different dimension to the need for better awareness. It again supports the need for a specialist NHS LD workforce (Gates, 2010). Not being used to working with people with LD was also seen by those allied-professionals who worked with people with LD in this study as a significant reason why prejudice and misconceptions about this client group arose.

As indicated above, there was a tension between the idea of social inclusion (the need to be treated the same as other people) and the additional needs that have to be addressed to enable people with LD to fully participate within society. The example above suggested that while people with LD can access services, to have healthcare delivered effectively meant that practitioners had to

understand that these clients had specific health needs which are different from those of the general population and that they needed communications tailored to their abilities (DRC 2006; Raitasuo *et al.* 1997; Turner and Moss 1996). This adds further weight to the criticisms of social inclusion being too narrowly defined in terms of access to services (Fyson and Simons 2003; Robertson *et al.* 2005) and is considered throughout the discussion. If people with LD are to be at the heart of healthcare, as suggested by the Scottish Government's Health Quality Strategy (2010), then training in their needs for all professionals requires to be incorporated into all training programmes. This may also mean that the way health promotion is delivered to people with LD will need to change to ensure that paid-carers are also able to conduct health education in order to support people with LD to undergo health interventions.

The least defined role was that of family-carers. Given the small numbers involved, few conclusions can be drawn from the findings in this study. It was clear that the role of mother or sister was enduring, whilst alternating between carer and family member was difficult. Service boundaries were clear: once the child reached sixteen years of age they transferred to adult services but this transition could be difficult for the family-carer to adapt to. This was often because it meant a change and reduction of services and, for some, relinquishing decision-making power. Making decisions about all aspects of their life is something that most people take for granted. However, as a consequence of their diagnosis of LD, people with the disability are constrained by the Adults with Incapacity Act (Scotland) (2000) about what parts of their life they can make decisions about. In this study, the family-carers were accustomed to making decisions and two had or were seeking formal decision-making power to remain involved in choices about care. In many respects being a family-carer incurs some form of 'paternalism' due to the limits on the woman's cognitive capacity to understand the world around her. For this reason the family-carers wanted to retain some control over care. Heather, who had not sought legal rights to retain an input into her daughter's care, had found the shift to her daughter making her own decisions difficult. This was compounded by being unable to be involved in aspects of her care, despite the fact that her daughter's decisions often had an impact on her life. This

highlighted the issues over the woman's autonomy and experience of sound decision-making. It also demonstrated that these family-carers would seek help about health problems which contrasts sharply with finding in the previous literature (Alborz *et al.* 2003; Beange, McElduff and Baker 1995; Kerr *et al.* 2003). Although other problems were highlighted about transition, it is not within the scope of this study to evaluate these. For this reason future policy needs to consider the views of family-carers and take account of the input that they have into the healthcare of the person whom they support.

Whereas a woman should have responsibility for her own health, in practice the level of LD dictated the discretion she was accorded. This was compounded by where she lived, whether her paid-carers saw health as being within their remit and whether there was input from the family-carer and or an allied-professional. Of note within the findings was the variable relationships between (and within) the allied-professionals, paid and family-carers. Relationships, especially communications, between the different personnel and organisations about the woman's health could be poor. This supported previous work (Taggart, Truesdale-Kennedy and McIlfatrick 2011). The key factor was the misperceptions which the allied-professionals, paid and family-carers held about the roles each played in supporting the woman with LD in health matters.

Examples of these misperceptions included the allied-professionals' belief that paid-carers needed more training about the health needs of the women, whereas family-carers were seen to put more credence on discussions of health with health professionals than with paid-carers. The latter belief held by family-carers was misplaced (as has already been discussed) since not all health professionals had an understanding of the heath needs of people with LD. The allied-professionals and paid-carers also believed that the decisions made about the woman's health by the family-carers often disempowered them. The same could be said for Heather, the family-carer who was not allowed to take part in the discussion about breast health with the nurses who visited her daughter. Another misconception identified was the difficulties about broaching health issues between the residential and day centre personnel because each believed the other would see this as interfering.

These findings are important because they add to our volume of knowledge and are of key importance to policy makers. In order to have a seamless provision of accessible and targeted health care for people with LD, the policy needs to encompass all those who provide support and care for those with LD. Recognising the discontinuities and discrepant perceptions within the each care sector (health, voluntary and social care) can help to address these problems and tailor health care needs accordingly, especially if translated in to a formal policy. The discrepancies around the social care sector pose problems in that some women may not be given the opportunities to attend breast screening if 'health' remains a separate issue. A simple solution would be to integrate health into the current social care sector. This seems simple in theory but would need to be enforced through national standards. This raises the issue of ensuring that such standards would be implemented and applied uniformly throughout the social care sector. Initially assurance may mean regular inspections throughout the social care sector to ensure such adherence.

7.3.2. Risk factors of breast cancer

Consideration of the risk factors for breast cancer was important since this adds weight to arguments about the need for women with LD to attend breast screening and related to box one in Figure 5. The findings in the literature review clearly demonstrated that women with LD had similar risks factors to women in the general population. Nulliparity increased the risk of breast cancer (McPhearson *et al.* 2006) and only Irene (woman with LD) had a child. This reflected previous work indicating that few women with LD had children (Carlson and Wilson 1996; Tarleton *et al. 2*007). In contrast to the general population, the risks from smoking and drinking were found to be negligible in this study as only two women smoked and most of the women only drank on occasions such as celebrations.

Little research exists on hereditary factors for breast cancer (see Schneider, Kieffer and Patenaude 2000) although family history has been found to be pertinent for women with DS (Satgé 2008). The experience of one woman (Irene) in this study adds to the body of literature. Irene had a known family

history of breast cancer but the protocol of offering prophylactic mammograms throughout her adult life to monitor her risk was not enforced. The reasons behind this were unclear. Although her paid-carer had queried this, it had not been followed up. My interpretation was that Irene had not been treated as 'every other' woman would have been, which supports the idea of Brown (1994) and McCarthy (1998) that the 'womanhood' of women with LD is often devalued. This similarly reflects their lack of social inclusion.

Key *et al.* (2003) identified that diet and exercise were also risk factors for breast cancer. The findings in this study demonstrated that food was used and understood in different ways. One way was as a 'treat' after attending breast screening, whereas a different perspective was put forward by Nelson (paid-carer), who suggested that food was a substitute for sex (although he was the only participant to raise this). In this he was referring to the 'empty lives' many people with LD experienced, such as not having a partner or close friend, and that food replaced this need. Within the findings, two women reported having 'friends'. However, the carers and allied-professionals mentioned that few of the women had 'friends' but rather saw paid-carers as their friends, which supports previous work (Foundation for People with Learning Disabilities 2004; Pockney 2006). Yet 'having a social life' is part of normal behaviour. This has implications for policy as women with LD are not socially included and policy makers should propose more help for women with LD who are socially isolated.

Related to this were activities such as shopping and going for coffee which were highly valued and regarded as 'a big thing'. Although these activities demonstrated that the women were seen within the community doing 'normal' things, they were timetabled into their day as activities. I therefore concluded that there was an argument to suggest that these women were not being included in society in a meaningful way, which supports work by Emerson (1992). My rationale was that there was an important difference between other groups, such as the elderly, in that people with LD have only recently had a more visible presence in society. Moreover, the above activities were not undertaken with friends or family which is similar to groups such as the elderly, although the elderly would normally have had some friends, even if their

numbers were dwindling due to illness or death (unlike women with LD who may not have had any friends). For this reason I believe that it is debatable whether these women were participating in 'normal' activities and whether they were undertaken in the same way as other minority groups. Once again there is evidence that the women in this study had not been included in social activities. It also suggests that the National Care Standards (2011) will require the building in of more meaningful activities. This may challenge current thinking within the social care sector about 'independent living' and may pave the way for developing more structured social activities with other people with and without LD.

Being overweight was associated with breast cancer (Blackburn *et al.* 2003; Key *et al.* 2003). One factor identified as causing the women to put on weight was having the normal freedom to live independently and to be able to go to the local shops to buy the food they wanted when the paid-carers were off-duty. This was in contrast to the more dependent women, as they relied on their paid-carers for their meals. It could be argued that the independent women were expressing their autonomy in eating what they wanted. However, just as with the rest of the population who over-eat, they were also damaging their health by doing so. This supports work by Grassick (2001). The difference is that unlike women in the general population, women with LD have carers who support them and their paid-carers may be challenged by their employer or GP over weight problems. This was problematic since they had to respect the woman's autonomy and independence but also had to be aware of their health needs. This aspect is rarely reported in the existing literature. Nevertheless, the women who lived alone were reminded about healthy eating and weight issues and were offered help with menu planning or cooking (Bell and Bhate 1992; Grassick 2001; Rimmer 1994; Melville *et al.* 2006). Introducing clearer guidance about autonomy may be one way forward but this would need to be undertaken by National Care Standards (2011) as they regulate the care sector. The practical challenge would be ensuring consistent enforcement given the diversity of staff who work within the care sector.

Poor nutritional understanding on the part of the paid-carers was also identified as a factor that contributed to the women's weight problems and reflects previous findings (Mencap 2008). David (allied-professional) took the strongest view, suggesting that it was the poor regulation in the carer sector that caused this problem because paid-carers only prepared and cooked meals that they had knowledge of. This may have been true, although this view was challenged by some examples in this study. For example, Pippa's paid-carer made low-fat rice pudding with strawberries and seemed conscious of the need to promote healthy eating choices. Little consideration was given by participants to weight gain being caused by psychotropic medication which suggests some lack of knowledge both by the allied-professionals and paid-carers (Einfeld 2001).

An area that compounded weight gain was the difficulty the women experienced in doing some form of exercise. In this study, the women who went to the day centre had more opportunities for exercise while some women's paid-carers helped them to obtain opportunities to exercise such as buying an exercise bike, requesting a 'befriender' (a volunteer who befriends a person with LD) and introducing in-house chair aerobics. The main problems with acquiring opportunities to undertake exercise (aside from the Scottish weather) were having support to do so, such as a paid-carer, respecting the women's choice not to undertake exercise or accessible facilities as indicated by Heather (family-carer), which supports previous work by Messent, Cooke and Long (1999).   These findings again highlight the problematic nature of 'social inclusion' in that there is an expectation that people with LD can simply use leisure centres whenever they want to. While the women had a theoretical choice of whether or not to undertake exercise, often practical issues such as lack of facilities or staff time prevented them from being able to exercise. Service providers need to address this if women with LD are going to be supported to engage in exercise and lead a more active life. This also suggests that there are inequalities with regard to exercise for this population and this is an aspect that future reviews of services such as '*Same As You'* (Scottish Executive 2000d) will need to consider.

In conclusion, box one of Figure 5 summarised the findings for the risks for breast cancer. It acknowledged that there are intrinsic elements, such as the woman's genetic inheritance, but also social and psychological factors such as eating and smoking. Key players identified in the diagram are the individual and their carers. The rationale for identifying the latter group as a 'key player' is that all women will have some type of support from carers. In addition, both the women and carers will either be aware or unaware of the risks of breast cancer. This has practical applications in that it raises issues about education and awareness of health issues for both the women and their carers. There are also a number of lifestyle risks; for example, if excessive weight is gained through poor understanding of nutrition. Allied-professionals only enter the situation once a problem has been identified and will then by default take a greater lead. Understanding the risks of breast cancer is important because this could initiate the breast screening journey earlier if there were hereditary problems or if the risk of breast cancer was increased because of inattention to general health. As stated above, education about the health problems of people with LD may lead to identifying problems sooner, but this again relies on adequate investment from the Government, and motivation from the women and the carers to make this happen.

7.3.3. Breast awareness

Surveillance of the breast was seen as part of keeping the breasts healthy by all participants and is represented by box two in Figure 5. In this study, eight of the twelve women said they checked their breasts, although what the women looked for, their knowledge and how often they checked their breasts varied. All the women purported to have received some health awareness education about their breasts but only four had good knowledge about how and what to check for in their breasts. Such poor knowledge and understanding in women with LD supports previous work (Davies and Duff 2001; Symonds and Howsam 2004) and is something that the NHS Cancer Screening Programme (2006b) has failed to acknowledge. Within the findings in this study was the suggestion that regular up-dates or reminders about checking the breasts were needed. This is an important consideration given the known problems with attention span and

memory within this population (Clare and Gudjonsson 1993; Dye, Hare and Hendy 2007; Tully and Cahill 1984). In the literature review, a number of studies advocated the need for information and intervention about how to check the breast, yet there was little mention about up-dating or reminding the women about what was discussed (Cowie and Fletcher 1998; Gaze 1998; Poynor 2003; Symonds and Howsam 2004). The need for up-dates to encourage the women to keep their breasts healthy reiterates the importance of education about breast awareness on an ongoing basis and in practical terms ensures awareness is maintained.

There were some questions around whether the women did what they said they did. For example, some women said they undertook breast self-examination but whether this was true was not known. Problems arose mainly with the more independent women where there were limited opportunities for carers to observe their breasts (due to not needing support with personal care), while watching the women undertake their breast checks would have been inappropriate. Relying on these women to report changes or lumps within their breast was problematic because they might be unaware of the significance, forget or be too scared to report it. Again the relationship with those who supported them and their knowledge was of paramount importance. There also needs to be more discussion about how women with LD could be facilitated to report finding problems with their breasts. Awareness of these women's needs should be embedded within the training of paid-carers and allied-professionals, which will have practical implications for the mandatory registration of paid-carers from 2011 in terms of keeping up to date with current practice.

Surveillance of the breasts was easier for women who needed personal care and a number of paid-carers disclosed that they undertook discrete checks when drying the woman. I believe that this 'invisible' care demonstrated a commitment to the health needs of the women. None of the paid-carers undertook formal examinations or palpated the breast but spoke about observing for changes in the breast as recommended by current policy (NHSCSP 2011). Paid-carers were also aware about not palpating the breast and the connotations that touching the breast had with sexual abuse (Royal

College of Nursing 1999). This demonstrated knowledge of breast awareness and current policy but also a motivation to ensure 'good breast health' in the women they supported. This refutes somewhat the claim that paid-carers have little insight into the health problems of people with LD (Janicki *et al.*2002; McCarthy 2002; Patja *et al.* 2001; Sullivan *et al.* 2003). The findings in this study suggest it is important to acknowledge paid-carers' contribution to the breast and general health care of the women. I also acknowledge that to maintain health monitoring and support health awareness requires continuity of care; however such continuity was identified as problematic in this study and influenced by the context in which care and support was delivered.

The sources of the information about keeping breasts healthy and breast screening were found to be similar to women in the general population – from the GP practice or family or paid-carers (Champion, Sugg and Skinner 2003; Sutton *et al.* 1994; Wyper 1990). With the exception of Wendy, few women had received information from their friends, which again provided new knowledge and suggested that social inclusion in terms of their social capital remained poor. One notable finding was that Honey had received her information from a course at her day centre despite the paid-carers from the day centre setting suggesting health was not part of their remit. This reinforced the notion that there was little standardisation of carers' views within the social care sector and presents an opportunity for the Social Care and Social Work Improvement Scotland body to develop policies to address this. Moreover, Honey also explained the importance of breast awareness to her sister which again demonstrates the value in health promotion. This again presents a practical opportunity to empower people with LD to keep themselves healthy.

A consistent finding in this study was that a popular source of information for the women was television soap operas. Veronica (paid-carer) commented that her clients took advertisements too literally, which supports previous work (Davies and Duff 2001; McCarthy 1999). Despite this, television and radio programmes such as Coronation Street and The Archers, have been used to convey messages on breast cancer awareness to the general population. In addition, Jade Goodie (a television celebrity) inadvertently increased uptake of cervical

screening through the publicity surrounding her struggle with cervical cancer (NHS Cervical screening programme 2009, Bowring and Walker 2010). This demonstrates how television can be used as a practical means of social inclusion in the everyday lives of the women with LD. In theory television may seem a useful vehicle to ensure health messages are raised within society as a whole. There remain practical problems for people with LD because they may not fully understand the message being conveyed (McCarthy 1998) and need support from carers to adequately comprehend it. To ensure the message being transmitted is clear, television programme makers would need to ensure that they consult with different sectors of society, such as people with LD and their representatives, to provide educational materials that can be used by a wide variety of groups in the population.

An aspect not addressed in the literature but apparent within the findings was a suggestion that the older women missed out on health education due to having been institutionalised. This issue has not been raised in within the literature on health belief models (Ogden 2005). Here the responsibility of monitoring their 'health' in accordance with current health policy (Scottish Government 2005) would have been removed and placed within the remit of the nurses. For this reason, more education was thought to be needed to help these women understand their health. This was in contrast to the younger generation of women with LD who were receiving more formal health education within the school curriculum alongside the rest of their age cohort in the general population. Health education starting at school also fitted in with current health policy, whereby the individual is considered to be responsible for their own health (Scottish Government 2005). This was seen to be an indicator of social inclusion in this generation of women with LD and making their 'womanhood' equal to other women in the general population.

What current policy such as Delivering for Health (Scottish Executive 2005) has failed to address is the fact that many women with LD may not be able to take responsibility for their health due to their level of cognitive ability. The vast majority of women with LD would need help, yet little consideration has been given as to how this might be addressed or achieved within current health

policy. Inevitably this would involve investment and funding. It also has to be remembered that Government policy only recognised the needs of this group of women in 2008, in the document *Better Cancer Care* (Scottish Government 2008). Once again social inclusion has been seen as requiring the integration of women with LD into the general health arena and regarding them as equal in terms of addressing their individual health. However, the means which might enable them to maintain their health effectively have in the main not yet been provided.

In Figure 5, box two represents breast awareness. I identified only the woman with LD as the central player here, because I believed that ensuring the women receive some awareness education about looking after their breasts could help them to understand more about the need for breast screening. Furthermore, the findings demonstrated that such education was somewhat *ad hoc* and that many women had the responsibility placed on them to report finding lumps. This raises a practical issue about the logistics of repeated awareness training and how this would be approached. The exception was those women who were more dependent on carers. However, whether the carers undertook surveillance was again inconsistent and dependent upon the philosophy of care in the area in which they operated. Education about surveillance depended upon where the woman lived and her individual activities; but again it was dependent on being referred to or being in contact with allied-professionals and the willingness of the carers to enable her to access this education. Theoretically, all women with and without LD should be offered education in breast awareness. However, for some women with LD this may not be practically possible due to their level of LD. This study identified that at present there is a more *ad hoc* basis and although current education policy is addressing this in schools, there remains a gap in terms of health policy for this older generation of women with LD.

7.3.4.   Preparing for breast screening

'Preparing for breast screening' was represented by box three in Figure 5. Within the findings, the discussions about breast awareness often included information about breast screening but for most women deciding about whether

to participate in breast screening was trigged by the arrival of the letter of invitation. As with all such invitations, the letter was addressed to the woman herself. This was identified as a problem for those women who lived independently because, unlike the women who were dependent, their letters would not be intercepted by the people who supported them. This meant there was potential for the appointment to be forgotten, or missed due to other competing health issues. Additionally, there was the issue of the literacy level of the recipient, as is the case for all women. These aspects reflect previous research on women in the general population (Bruyninckx *et al.* 1999; Djuretic *et al.* 1999; Hamilton and Barlow 2003; Keefe *et al.* 1994; Pearson *et al.* 1998; Reynolds, Stanistreet and Elton 2008; Wood and Douglas 2007). The vast majority of people with LD are unable to read. For those that can, the content of the letter may cause anxiety because of them being unsure about the nature of the procedure. Although adapted letters are available, the findings again reflected difficulties of knowing who needed to receive them. These issues were reflected in the previous literature (Isaacs 2006; Pearson *et al.* 1998). In this study, the mammographers disclosed that they kept their own database about additional needs for their clients to overcome this issue. However, such an informal system may mean that some women with LD may not be identified as having particular needs. Overall, the problems of data sharing are something that health policy *per se* needs to address.

As well as the need for an adapted letter, a mechanism that could automatically trigger a double appointment and the chance to look around the department if it was appropriate was also required. Meeting the staff and having a look round the breast screening unit may help women to understand what the procedure involves and help to reduce anxiety. This issue has been raised in the literature (Davies and Duff 2001; Isaacs 2006; Sullivan *et al.* 2003; Sullivan, Slack-Smith and Hussain 2004). This was seen to be applicable to other health procedures and would dispense with the need to remind paid-carers that these services were available, since not all the paid-carers may know about them. The drawback of implementing this proposal would be the resources needed, such as someone to accompany the woman to the breast screening centre and the time of the mammographers. In the current economic climate, this may not be

feasible although the value for the patient experience needs to be balanced against the resource implications.

An additional factor raised in this study that adds to the body of existing literature was the influence of the literacy level of the paid-carer. This was seen to be an influential factor because they may be unable to disseminate the content of the letter. In this study all the carers were literate, although it has to be acknowledged that if they were not they may not have participated in the study for fear of being exposed. If the carer has poor literacy, there is the potential problem that they would not be able to disseminate the content of the letter or else might simply ignore it which will have practical consequences for the women. For example, this would mean that the women would not be fully informed about the opportunity to have their breasts examined or decide whether or not they wanted to participate in breast screening. This may impact on the low up-take of breast screening in this group of women.

The findings indicated that the way that breast screening was broached may have influenced the woman's final decision about participating in the procedure. This varied depending upon the woman and the support she received. Discussing breast screening with the woman was acknowledged as difficult by those who supported them. This was because it was difficult to know what the women had understood. This aspect was reflected in the literature (Davies and Duff 2001) and in the health belief model (Ogden 2005). For this reason, having a rapport or 'knowing the woman' was identified as important in this study because a carer could pitch the discussion in a way that took account of the woman's level of understanding. This supports previous work (Donovan 2002; Singh 1997).

How the topic was broached with the women was found to vary. Some paid-carers like Elaine would discuss the issue with the woman and then bring in other colleagues or allied-professionals if she believed the woman needed more help to understand the information. In contrast, Emma's colleague put the letter of invitation to breast screening in the bin because the woman did not want to discuss it, which was not indicative of a full and informed decision. These

differences suggested that the levels of discussion were on a continuum and helped to account for why some women never presented at breast screening. The organisation that regulates paid-carers (Social Care and Social Work Improvement Scotland) may need to look at this issue and give clear guidance for paid-carers. This is also pertinent if women with LD are to be fully included in the breast screening programme.

Whether breast screening is appropriate for women with severe or profound LD has been raised within the literature (Satge´ and Sasco 2002; Sullivan and Hussain 2004; Wilkinson and Cerreto 2008). In this study, those who supported women with severe and profound LD spoke specifically about the problems they had in discussing health matters with their clients, which again adds to our knowledge. Although three paid-carers who worked specifically with women with severe and profound LD had not broached breast screening specifically, they acknowledged that the decisions about participation would be made for these women. Any decisions made would adhere to the guidance from the Adults with Incapacity (Scotland) Act (2000) and involve the wider team responsible for the woman's health care. These discussions would consider the necessity of the procedure, the distress it would cause and the need for sedation. This may require further investigation before it is included in a formal policy as guidance for practitioners and paid-carers working in this area.

Within the findings, those who supported women acknowledged that their clients often had additional health issues, especially those with severe and profound LD. Many of these women had multiple appointments and some found it difficult to attend clinics due to behavioural problems or the prospect of having an unpleasant procedure undertaken. For this reason, it was suggested that there was a hierarchy in terms of necessity for procedures. In comparison with others, breast screening was seen as an 'unnecessary' procedure, and thus identified another factor for these women not attending. These findings were similar to previous work on women with cognitive impairments or physically disabilities in the general population (Wolfson *et al.* 2001). This has not been broached either within the work on the health belief models, social

inclusion or womanhood (Brown 1994, MacIntyre 2008; McCarthy 1998; Ogden 2005).

In order to help the women attend appointments, sedation was sometimes considered. In this study, the use of sedation was reported for a number of interventions such as dental work and cervical screening. The use of sedation has been raised in the literature on cervical screening but not within the context of breast screening (Quint and Elkins 1997; Jaffe *et al.* 2002, Jaffe 2005; Wilkinson and Cerreto 2008). Sedation may help the woman manoeuvre into position and feel more relaxed, but it may create other difficulties since the procedure requires the woman to stand upright. If this was more widely adopted, there would be a need for guidance and policy for those working with clients who had been sedated and a need to ensure all practicalities were covered for all eventualities.

Access to breast screening is open to all women since the scrutiny of breast screening lists by GPs was ended in Scotland (Weller 2006). Despite this, one paid-carer revealed her client with severe LD had received a letter from her GP suggesting it was not appropriate for her to attend mammography. Epidemiological evidence suggests that people with severe LD have a shorter life expectancy which reduces the risk of them developing cancer but this should not be used to deny these women access to this service (Hogg, Northfield and Turnbull 2001). It may have been more appropriate for the GP to have considered alternatives such as ultrasound and/or surveillance, although both are seen as less accurate than mammography (NHS Cancer Screening Programme 2006; Satgé 2008). This is also an area where clearer guidance is needed. Although this case was raised by only one participant, it demonstrated that there were still some misconceptions about the health needs of women with LD and their right to the same health procedures as all women.

When discussing breast screening with the women during this study, I used pictures and tailored my language to the woman's level of understanding. Pictures helped to make the concepts more concrete. The materials (CD and booklets) that were used in this study were locally produced by FAIR, which

some allied-professionals had helped to develop. The Breast Screening Unit was also producing a CD to support women with LD and those women with poor literacy. The findings revealed that there were some criticisms of these resources. There was acknowledgment that the FAIR materials were not suitable for all women, and were either too simple or not simple enough for the women and that few resources were aimed at women with severe and profound LD. Additionally, some women may need support with reading and most women would need someone with whom to discuss the content of the resources; these issues are rarely raised in the literature.

Given the different environments in which the women lived, not all women received the same assistance about discussing health matters. Some paid-carers may not see it as within their remit whilst others may not have the knowledge or confidence to discuss breast screening. The latter issue was reflected in previous work (Davies and Duff 2001; Isaacs 2006; Poynor 2003; Royal College of Nursing 1999; Smyth and Bell 2006; Sullivan, Slack-Smith and Hussain 2004). Using CDs was also identified as problematic for the women who lived in group housing in terms of having enough privacy to watch the CD. This issue may need addressing within the guidance given to paid-carers.

A number of carers in this study had not seen some of the resources or did not know how to obtain them, which was consistent with previous work (Taggart, Truesdale-Kennedy and McIlfatrick 2011). In this study, Clare (allied-professional) acknowledged having a number of resources but never having used them with women with LD in her practice, which was an issue raised by a colleague about other work (Levi 2006). The cost of the FAIR resources was a minimal charge of one pound but other material by Hollins and Perez (2000) was ten pounds. Cost had to be considered because it could be a deterrent, especially since breast screening occurred once every three years whereas resources about diet, diabetes or heart problems may have more universal application. Again, these findings have not been highlighted in the existing literature.

The findings revealed that there was no uniform terminology or consistent level of detail used to describe breast screening, although comparison to an 'x-ray' was commonly employed, despite acknowledgment that not all women would have experience of an x-ray. Discussions were found to vary and related to the woman's level of understanding. Often explicit examples were thought to be needed, such as '*strip down to the skin and be exposed*', in order to ensure that the women had enough information to make a decision and also knew what to expect. The word 'cancer' was not used consistently because of the fear it could evoke, which is true for all women. Usage was pertinent to each individual woman (if friends or family had died of cancer or they knew the terminology) and their level of understanding. This contrasted with the advice the women gave as they were more direct: for example, Honey alluded to the terminal consequences of not attending breast screening appointments. Although the use of plain language is highlighted and recommended in the literature (Isaacs 2006; NHSCSP 2006) little information exists about how to discuss issues with women with LD or the content that might be discussed. Some booklets such as Fair (2005) and Hollins Perez (2000), NHSBCSP (2006), offer suggestions, but again these are aimed at more able women. In this study, the key factors identified by the women about breast screening were undressing, the size of the machinery and the breast being squeezed on a cold plate which can be painful. This is useful knowledge when discussing breast screening with women with LD.

The predictive health models (Ogden 2003) suggested that decisions about screening were based on personal experience and the individual's values. Breast and cervical screening both involve undressing and having to have sexual organs examined. This was identified as a barrier in this study and reflected previous work in both the general and LD populations (Borrayo and Jenkins 2001; Davies and Duff 2001; Isaacs 2006; Sullivan *et al.* 2003; Sullivan, Slack-Smith and Hussain 2004; Truesdale-Kennedy, Taggart and McIlfatrick 2011). A factor that all three groups of participants commented on was poor experience of health appointments. Two women declined to go for breast screening: one gave no reason for this decision while the other identified repeated poor treatment in hospital as having put her off attending other

appointments. This supported previous findings (Sullivan, Slack-Smith and Hussain 2004) and also the work from the theoretical models (Ogden 2003).

Family-carers, especially parents, have often been identified as barriers to screening (McIlfatrick, Taggart and Truesdale-Kennedy 2011). Again, these findings were supported in this study. When the family-carers were asked, they were all in favour of breast screening whilst only Vicki was reluctant to allow her daughter to attend cervical screening. The reason behind this was the mixed messages that screening gave out, in that it was difficult for her daughter to understand who was able to touch her in the vaginal area and who was not. This rationale also lends itself well to the beliefs of the allied-professionals who suggested that older women with LD would find this difficult because of their up-brining, in that many institutions discouraged sexual expression and the theoretical ideas of repression of sexual expression were identified in the literature (Garbutt 2008). The premise put forward was that screening confused the women about when they should undress and who should touch intimate parts of their body and this would be compounded by their lack of health education. This aspect has not been raised in the literature and is an important consideration for women with LD who may be unable to differentiate between a trained healthcare professional and an abuser.

The findings in this study suggest that women with LD would not have been habituated into attending screening, unlike women in the general population who regularly attend screening and see it as part of their health routine (Cribb 2002; Skrabanek 1988). This perception seemed somewhat misplaced because both screening programmes for breast and cervical screening were launched during the 1990's, around the same time that the closure of institutions was occurring. There was a possibility that these women would not have been habituated into screening, especially cervical screening (which starts earlier than breast screening), because they were not seen as being sexually active (Djuretic *et al.* 1999; Pearson *et al.*1998; Stein 2000). This belief was misplaced because it did not account for those women who had experienced sexual abuse or had children, as Kastner, Nathonson and Friedman (1993) highlighted. As a result, when these women became eligible for

mammography, they would not have been habituated into screening. Furthermore, there was a possibility that the same attitudes about cervical screening were seen to overlap with breast screening. Rather than being eased into screening programmes at their inception along with all women, women with LD were denied the opportunity to participate by healthcare staff because they were unaware of the needs for these women to attend. This gives a different dimension for explaining poor uptake of breast screening by women with LD and adds weight to the theoretical arguments about 'womanhood' being devalued (Brown 1994; McCarthy 1998).

A consistent finding within the literature was an emphasis concerning the need to attend breast screening (Pehl and Hunt 2004; Isaacs 2006). Although the allied-professionals and carers believed that the women should attend for breast screening, they acknowledged that the women who declined to go for mammography should have their decision respected (even if it went against the judgement of those who supported the women). These findings suggest that the women were not pressurised into attendance for screening in order to maintain the 'norm' and could make their own decisions, which endorses the theoretical work previously presented (Cribb 2002; Keywood, Fovargue and Flynn 1999; Skrabanek 1988). This is a refreshing addition to the literature because it presents women with LD as equal partners, able to make decisions about attending for breast screening just as any woman in the general population would do and highlights a good example of social inclusion. In stating this, there needs to be some follow-up procedures put in place to ensure that these women are not being disadvantaged because of their level of LD and their level of understanding about their health or certain procedures and to ensure there are no problems with their breasts.

In Figure 5, 'Preparing for breast screening' identifies all three participant groups as key players. This study disclosed that the quality and detail of preparation varied from woman to woman and was determined by their level of LD. The philosophy of care of her carers and whether she had been in contact with allied-professionals also posed practical problems about the type and strength of preparation she may receive. As with women in the general

population, women with LD were exposed to literature and television messages but not all women with LD would have the potential to take these messages on board. This is rarely highlighted in the theoretical literature. For some women with LD, this stage could mark the end of their breast screening journey if they decided not to proceed further or their carers felt it was inappropriate. At present some women go no further and what is needed is some clear guidance for allied-professionals and carers at a national level about surveillance of breast problems in this population. Although there is some, it needs to be tailored specially to those working with people with LD.

7.3.5.   Attending for breast screening

'Attending for breast screening' related to box 4 of Figure 5. The findings indicated a high uptake of breast screening in this study, with nine of the twelve women having been for breast screening. Generally poor uptake of breast screening is reported in the literature with the exception of Biswas *et al.* (2005), Davies and Duff (2001) and Gesualdi (2006). However, the review *Health Needs Assessment Report: People with Learning Disabilities in Scotland* (NHS Health Scotland 2004) also identified poor up-take of screening services by women with LD. The reasons for the high uptake displayed by the sample in this study were not certain, although a quarter of the women had experienced breast problems which necessitated having a mammogram. These women were also more knowledgeable about their breast health and the necessity of the mammogram. Two of these women had also been diagnosed with breast cancer and this warranted compliance with breast screening to ensure the cancer was monitored. Compliance was linked to their anxiety about the cancer returning. Knowledge about breast awareness was also displayed by one woman, Honey, who had attended a course on the subject. She had also imparted this information to her sister. This suggests that good understanding of breast awareness and breast cancer, as well as experience of mammograms, were factors that facilitated attendance at breast screening. These findings supported previous studies (Davies and Duff 2001; Isaacs 2006; Pehl and Hunt 2004; Proulx *et al.* 2008; Sullivan *et al.* 2003; Sullivan, Slack-Smith and Hussain 2004).

Resistance to attending breast screening was found only with Wendy (woman with LD). She had experienced poor treatment from nurses and doctors in previous hospital appointments which helped to explain her reservations about participating in breast screening. This fitted with the health belief models (Ogden 2005) in that preconceptions can impact on health behaviour. It also reinforced the necessity to listen to such views in order to put the women's feelings at the heart of health policy and improve healthcare in the future (Scottish Government 2010). In this way these women can be included as equal partners rather than excluded from women's health care.   Another factor raised was having competing health problems, since two women said that their long-term health problems decreased their motivation to keep healthy and is consistent with views held in the general population. Those who had previously attended for breast screening also noted that the pain had put them off returning (see below, section 7.5.6).

When having a mammogram these women's experience was dependent upon how well the carers and allied-professionals were able to work around an immovable system. This also depended upon how well the woman had been prepared (which would be unique to each individual) and what additional requirements were in place to facilitate the mammogram. All the women in this study had been accompanied to breast screening by their paid-carer. In rare circumstances, such as the woman having no carer to support her, the Community LD Nurse would take her to the appointment and give support. Providing reassurance and discussing what breast screening would entail were identified as key factors in facilitating attendance in this study and something future policy and guidance on breast screening should emphasise. These elements were seen to be built up through the preparatory work by the carer and or allied-professionals prior to the woman attending for the mammogram. Whether the carer or allied-professional accompanied the women into the room where the mammogram was undertaken depend upon whether the woman was independent or dependent. In this study many dependent women went into the room without their paid-carer.

For the woman to have a good experience of breast screening there needed to be better joint working by the allied-professionals i.e. mammographers, and paid-carers during the procedure. Within the findings, it was found that this did not always happen as the observation with Annie (woman with LD) and her paid-carer (Fergi) demonstrated. Here Fergi offered to stand with Annie during the procedure to keep her still and believed she was more able to instruct Annie about what to do. The mammographers would not allow Fergi to do this and Annie became frightened. I also believed Fergi's proximity would have made Annie's experience more positive. In the discussion afterwards with Annie, Fergi and the mammographers, there were clearly mixed feelings about the roles each other played. Annie was glad it was over but had been frightened, whilst Fergi was angry about the way the mammographers treated Annie. The mammographers had contradictory views, saying that they needed carers to help them but also used Annie's behaviour to highlight the problems they have screening women with LD. What they did not identify was the impact that their behaviour had on the woman's experience and perception of having a mammogram. This strengthens Truesdale-Kennedy, Taggart and McIlfatrick (2011) argument that having friendly staff makes the experience easier for women with LD and something that is omitted in the NHS Cancer Screening Programme guidance (2006b) and *Better Cancer Care* (Scottish Government 2008). On a practical basis this is something that could easily be addressed and should be considered in future policy.

My interpretation was that the mammographers in this observation were unsure of how to work with these women or respond to their needs and this reflected findings in the existing literature (Davies and Duff 2001; McIlfatrick, Taggart and Truesdale-Kennedy 2011). This problem was also raised by other carers, allied-professionals and the women themselves. Mairi, for example, had explained that she was nervous, yet the mammographers interpreted this 'nervousness' as being due to her wanting to terminate the procedure. A factor that increased her anxiety was having painful limbs manoeuvred by the mammographers to achieve an optimal mammogram. This problem could have been solved by ensuring that analgesia was taken prior to the appointment. This suggested that mammographers needed more support to work effectively with women with

LD whilst undergoing a mammogram and this will inevitably need to be embedded with their training. This was pertinent in this study because the women here had clear distinctions between what they liked and what they disliked, such as the pain of the mammogram which was identified as a deterrent in this group of women. If the Scottish Government is committed to putting patients at the heart of healthcare in polices then these views must be listened to and incorporated into future approaches to health care.

In relation to Figure 5, the allied-professionals are identified as the key players at this stage. As the findings suggested, how they respond to the women with LD and work with the woman and carers was crucial. I acknowledge that the woman herself could also impact on this part of the journey, as could the carer, but since the mammographers are the ones carrying out this procedure, most of what happens is dictated by them. Once again the journey could be interrupted as the woman might get this far yet not have the mammogram. As stated previously, there should be clear guidance in the form of care standards for carers on what to do in this situation in order to ensure that these women's health needs are met. This may also mean having the opportunity to return to try again several months later, which would mean a change in the current provision of breast screening of one attempt every three years.

7.3.6.   Experience of having a mammogram

The experience of having a mammogram was related to the final box, box 5, in Figure 5. This represented the culmination of all the preparation that surrounded the breast screening process and the different influences that the women, carers and allied-professionals exerted on each part of the process.

The women described breast screening as painful and cold and were also anxious about the procedure because of the machinery involved. Pain and anxiety reflected previous findings within the literature on women with LD as well as the general population (Burack *et al. 1*998; Davies and Duff 2001; Frazier *et al.* 1996; Isaacs 2006; McIlfatrick, Taggart and Truesdale-Kennedy 2011; Marrazzo *et al.* 2000; Sheeran and Orbell 2000; Sullivan *et al.* (2003),

Sullivan, Slack-Smith and Hussain 2004). The experience of the procedure being 'cold' indentified by the women in this study was not noted in the literature. Within the narrative, two women who had both experienced breast cancer spoke about the necessity to go for breast screening to ensure that the cancer had not returned. These women were able to reconcile this painful procedure (breast screening) with the need for reassurance that their breast cancer not returned. In order to make light of the procedure and help women cope with the pain, as well as the embarrassment of having a mammogram, Irene (woman with LD) had named the procedure 'the orange squeezer'. This indicated that she had accepted that the procedure was necessary and that this was her strategy to cope with this procedure.

In this study few allied-professionals or carers had mentioned that breast screening was painful, which was in direct contrast to the women's experiences. I believed they did not speak about the pain for two reasons. First, few carers or allied-professionals had experienced breast screening first hand and were not aware what it was like. This is not to suggest that experience of mammogram was imperative in discussing breast screening. However, it can uncover details that are not found in the literature which could be pertinent in preparing the women. It also emphasises the usefulness of training and awareness of breast screening for those working with older women with LD. The second reason was that suggesting to the women that breast screening might be uncomfortable could deter them from attending. This again relates to previous discussions about having to attend other unpleasant health procedures such as at the dentist, which might also be compounded by their polarised thinking.

Strategies to enhance the experience of breast screening were also discussed, although the main problem was working around a fairly rigid system. Longer appointments than the standard 'six minute appointment system' was a common theme, although even double appointments were seen as being too short for women with LD which supports previous work suggesting the need for longer appointments (Isaacs 2006; NHSCSP 2006). Innovative ways to facilitate the experience such as paid-carers attending for their breast screening

appointment at the same time as their clients and allowing them to accompany them were also suggested. This certainly adhered to the idea of 'womanhood' (Brown 1994; McCarthy 1998) in that it was not just the women with LD who had to go for an 'unpleasant' procedure but all women. An interesting proposal was put forward by Joyce (allied-professional) who suggested that if the first attempt at breast screening failed the women could try again a little later, rather than waiting for a full three years. The former would be hard to implement whereas the latter would be dependent on the resources available, and would mean a change in policy about breast screening in that it would need to be more flexible. These suggestions demonstrate the commitment to assisting the women through breast screening by many of those who supported these women. Another factor to consider is that the women are used to a person-centred approach to care, whereas when they attend mammography the care reverts to a medical system of care. These two approaches to care operate very differently and may impact on the overall experience of mammography. With the move towards putting the patient at the heart of healthcare (Scottish Government 2010) this would mean an overhaul in the delivery of healthcare within the Scottish NHS.

A final point about the implications of the experience of breast screening for women with LD was that it was indicative of whether the women would return for future breast screening appointments. In this study the experience of mammography, insofar as it was painful, was a factor that deterred the women from re-attending.

As already indicated, box 5 of Figure 5 represented the experience of having a mammogram. Here all the players were identified as central, since they would have exerted different influences along the journey, resulting in a unique experience. This demonstrates that there is the potential for each group to exert influence throughout the journey and this can impact on the overall experience. Along the way there is also the potential for equality or inequality of delivery. This is an important consideration if women with LD are to play a part in shaping the service delivery and adhere to the vision presented in the Scottish Government's Quality Strategy (2010). To ensure that women with LD are at the

heart of health care, their views need to be heard and this means more consultation with them about health matters that affect them.

7.4. Summary

The evidence presented within the discussion and in relation to Figure 5 identified that attending breast screening for women with LD should be viewed as a process (indicated by the five boxes). There is potential for equality of access in breast screening, although this is dependent on a complex range of issues and relationships as identified above. However, for those who do access breast screening services, potential exists for inequality in the delivery of the service for women with LD. For such women to enjoy full social inclusion and have their needs met, their views need to be listened to, since this is the only way policy makers can put women with LD at the heart of health policy. As yet, women with LD have limited equality in terms of being treated equally or being seen as equal within society.

7.5. Answering the research questions

Having discussed the key findings from the study, I will demonstrate that I have satisfactorily answered the research questions.

How do women with LD experience breast screening?

This question was answered by the findings from the cross-analysis in the theme 'G*oing for a breast screening test'*. The women's experience of breast screening was negative in that they described feelings of cold, embarrassment, fear and pain. With the exception of coldness, this supported work in the general and LD populations (Gregg and Curry 1994; Lostao *et al.* 2001; McCaul *et al.* 1996; Truesdale-Kennedy, Taggart and McIlfatrick 2011). Essentially, the experience of breast screening depended upon the preparation the women had received, their understanding of the procedure and if they had experienced problems with their breasts prior to attending mammography.

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What are the factors that influence women with LD to participate in breast screening?

This question was answered by the second theme of the cross-analysis *'Getting through the door of breast screening.'* In essence the findings demonstrated that the decision about whether to go for breast screening was mainly determined by the woman's level of LD, how she was prepared for breast screening and the beliefs and philosophy of the people who supported her. This made each woman's story about attending breast screening unique to the woman and her environment. One of the most important factors influencing attendance for the procedure was the ability to work within and around the rigid process of breast screening. That said, there were a number of similarities which facilitated or deterred the women from attending breast screening. These included facilitators such as the degree of reassurance, preparation, support and understanding the needs of women with LD; and barriers such as pain, poor hospital experiences, embarrassment and sedation. Many of these factors were consistent with previous work on women with LD and the general population (Davies and Duff 2001; Guilcher Newman and Jaglal 2010; Isaacs 2006; Nosek and Howland 1997; Poulos *et al.* 2006; Proulx, *et al.* 2008; Sullivan *et al.* 2003, Sullivan, Slack-Smith, and Hussain 2004; Truesdale-Kennedy, Taggart and McIlfatrick 2011; Wee *et al.* 2000).

7.6. Strengths and weaknesses of the study

In this section I will reflect upon the impact of the methodological choices in this study. I will consider the data collection method, access and recruitment strategies, data analysis and presentation.

In this study data collection was undertaken using observation, semi-structured interviews and field-notes. The quantity and richness of the findings were indicative of the success of this strategy in eliciting in-depth views and accounts of experiences. The interactions observed contextualised and complimented data uncovered during the interviews whereas the semi-structured interviews enabled me to tailor questions to the individual needs of the participants. This

allowed them to recount their experiences and focus on issues that had salience for them. These methods reflect the understanding of interviewing people with LD (Booth and Booth 1994, 1996; McCarthy 2002; Taylor 2005). The use of pictures again was consistent with practice within the field and enabled the women who were less verbal to still give their views and experiences (The Department of Health 2001b; McCarthy 1998; McCarthy and Millard 2003). My field-notes enabled further reflection on matters that arose in the field.

Recruitment of participants from the NHS, voluntary and social care sector resulted in a sample of people that reflected the area more closely than other similar studies (see McIlfatrick, Taggart and Truesdale-Kennedy 2011; Taggart, Truesdale-Kennedy and McIlfatrick 2011; Truesdale-Kennedy, Taggart and McIlfatrick 2011). The sample enabled family-carers to be given a voice and an insight into decision-making by those who represented women with severe and profound LD. Within the sample of women were participants who had not gone for breast screening, those who had and those who had experienced breast cancer. This gave a richer narrative as views from most of the key stakeholders were heard.

Access to the field and participants in this study demonstrated a number of difficulties. Had I not had the contacts or undertaken previous work I believe I would have experienced more difficulties in approaching the areas and participants and would not have had access to experienced advisors from the LD sectors. These factors reflected the large amount of groundwork that was undertaken prior to this study. This is an important message to communicate for future researchers planning to undertake work in this field and reflects the literature on accessing areas (Bonner and Tolhurst 2002; Nind 2008; Pope and Mays 2006; Wallace 2005; Walmsely and Johnson 2003).

To gain access to the participants and areas I had to use gatekeepers, an approach which has advantages and disadvantages (Bryman 2008). In this study the use of gatekeepers was a requirement of the ethical approval from COREC and was generally unproblematic, although there were some

exceptions. One day centre I contacted refused permission for me to undertake the study with the women because they did not see health as part of their day centre remit. As a researcher one has to respect such decisions even if the judgment appears difficult to accept. My disappointment at this decision was because most day centres would have to manage menstruation, epilepsy or diabetes on a day-to-day basis with some of their clients. This alerted me to the differences in priority within each day centre in terms of their work and remit and the difficulties of undertaking research in this area.

In some areas I had to seek the permission of the woman's paid-carer as this was seen as 'best practice'. Three paid-carers declined granting permission for me to interview the woman with LD. Again I respected the paid-carer's decision although I firmly believed that a woman who has capacity should be able to take part in a study if she wanted to. I do, however, acknowledge that the paid-carers would know the capacity of the woman better than myself in terms of being able to cope with being interviewed and I was mindful of what Dines and Cribb (1993) suggested was the 'we know best' attitude. I trusted that this was the basis of their decision. Having worked with people with LD from 'cradle to the grave', I believed that I would have picked up any problems during the interview. These issues again add weight to the findings of this study in that there is little consistency about how decisions are made within the area for and with women with LD and that they display a wide spectrum.

The data analysis framework developed in this study was based on the work of McCarthy (1999), Smith (1999) and Smith and Osborn (2003). These studies provided me with a structured framework from which to approach data analysis. Although this was not a 'tried and tested' framework, it acknowledged data analysis methods that had been used within the general and LD populations. I also believed it was also important that the views of the women were analysed utilising the same framework as that employed for the carers and allied-professionals. This was because I believed there would be more consistency across and within the findings, especially since I subjected the findings to a cross-analysis to synthesise the views. By doing this I also acknowledged that one set of views was no more important or valid than any other set of views.

The choice to present the views of the women, carers and allied-professionals individually offered an opportunity for the 'interpreted' voices of the participants to speak and express their experiences. The choice to present the findings in the discussion through the cross-analysis was informed by my desire to bring these voices together, as well as offering my interpretation of the meaning of these experiences. Using the cross-analysis to discuss the findings was exciting but also daunting. I was concerned that the women's voices should not be lost. However, I believed the cross-analysis offered a deeper overview of the analysis and captured the salient factors within the combined data.

Adhering to the principles of inclusive research enabled the women to set the agenda, advise on the questions and confirm the analysis. This reflected previous work undertaken in this area (Chappell 2000; Kiernan 1999; Northway 2000; Walmsley 2004a,b). Whether the recommendations will improve the women's experience cannot be ascertained upon completion of the thesis, but will need to be considered in the fullness of time if breast screening services are to meet the needs of women with LD, although they highlight the timeliness of such a study in terms of the Scottish Government's quality strategy (2010). Nevertheless, the research has given a voice to the women about their experiences of breast screening and the factors that have influenced their decision to participate in it or not.

There were a number of limitations within the study which placed particular boundaries on the ability to generalise from its findings. The focus of this research concerned the experience of going for breast screening in women with LD. Within this study, experience is theorised as being the product of beliefs, values, previous experience, attitudes, knowledge and other personal variables. These factors underpin the process of interpreting the situation that the individuals were being asked about. Thus, the same situation may have been interpreted differently by each individual since they would draw on differing experiences and beliefs. Despite this, the findings indicate that although there were differences between the participants' experiences, there were also similarities. These similarities represent a shared or common experience. It can therefore be assumed that the participants' experiences will have commonalities

with other women with LD going for breast screening. This means the findings can be used to sensitise practitioners to the possible experience of others, whilst not being assumed to be directly transferable.

The experiences captured through the observation and interviews were constructed between researcher and participant, within a particular social and historical context. It follows, therefore, that the findings arrived at here will not be replicable by another researcher or in another social or historical context.

The sampling method and sample size also place limitations on the ability to generalise from the findings. The sample size in this study was limited by the practicalities of dealing with large amounts of data. The purposive nature of the sample meant that the findings are not representative of the general population of women with LD, allied-professionals and paid and family-carers (such as might be achieved by the employment of a randomisation strategy). The participants were drawn from different sectors, worked regularly with a range of women with different levels of LD or only worked occasionally with women with LD. Hence the findings can only represent a snapshot of experiences of participating in breast screening in Scotland. The value of such data is that it sensitises the reader to the issues that are presented within the findings and to the women's understanding of their experience.

The use of observation as a research tool in the field of LD needs to be addressed. The small number of observed behaviours related to two factors. The first was that some participants were not engaged in activity around breast screening and this was to be expected. The second problem, which is more pertinent for future research, was the issue of consent to observe in areas. It was clear that a number of participants had concerns about agreeing to participate in the observation part of the study due to concerns over their clients who did not have the capacity to consent to being part of the observation. This is not to say observation cannot be undertaken but rather that further protocols may need to be in place prior to observation taking place for these clients.

7.7.   Reflections on the study

It would have been more difficult for someone with no prior experience of the LD area to undertake this study because of the relationships that needed to be in place in order to gain access to the various actors. Even so, as has been shown, access was not always granted. Unlike previous research, I tried to embrace all the sectors that a woman with LD might come into contact with: the voluntary or independent sector, social work departments and the NHS. In doing so I set myself a challenge to capture all perspectives and make sense of each culture. What I found was a myriad of opinions, most notably demonstrated within the findings from the paid-carers. Despite the ambition of this approach, I believe that I have achieved its aims.

There are still some voices that have not been fully captured – those people who do not work consistently with people with LD, mammographers and family-carers – as well those who remain voiceless – GPs, women with severe or profound LD and social workers. There is more work to be undertaken but, in retrospect, I now realise why only certain sectors (such as the health or social care) have been targeted in previous research. Proceeding in this way, I feel I have uncovered some of the intricacies within the field, especially the different perspectives on service remit. However, I am aware that this is only a very small snapshot and does not represent everyone within this area. Having so many different perspectives made the analysis more challenging. Nevertheless, through a developmental process of trial and error, the perspectives of participants were captured, as the themes and sub-themes demonstrate. Again, acknowledgement is made of the small numbers representing some participant groups.

What I have learnt is that the area of health in this field is more complicated than I first imagined. Attention to the differences between women who are independent and dependent as well as their life experience and current position was important, as were the variations between and within services and the impact these had on the women's health. Despite these complexities, the findings have shed new light on a topical area. They have supported much of

the literature and in places supplemented or challenged it. It is concluded that new ground has been broken in this area, insofar as the research acknowledges the views of the women and their experiences, as well as the perceptions of those who deliver breast screening and support the women through this procedure.

7.8.   Summary

This chapter has discussed the views and heuristic diagram that were brought together by the cross-analysis and explored the strengths and limitations of the study. The final section constitutes my own reflections on the analysis and demonstrates that the research questions have been answered. The main thrust of the chapter was to piece together the factors that facilitated or hindered participation in breast screening along with a discussion of how these findings related to the current literature. The key elements of this study have shown that going for breast screening depends on a number of influences which are underpinned by the level of the LD, who supported the women and the philosophy of the organisation they work for, and who prepared the women and the level of preparation the woman received. Along with these was the ability to negotiate around the inflexible system of breast screening. The principal conclusions of the study are presented in the next chapter along with a summation of their contribution to knowledge and recommendations for future research.

Chapter 8:   Conclusions and Recommendations

8.1.   Introduction to the Chapter

This Chapter presents the conclusions based on the findings discussed in the previous chapters. A number of recommendations derived from the findings are then reviewed before offering some suggestions for future practice and research.

8.2.   Conclusions

The methods used facilitated the gathering of rich data. Detailed analysis generated a comprehensive picture of the experience of women with LD of participating in breast screening in Scotland and the factors that influenced their participation in this procedure. The presentation of data gave the reader access to the individual and common experiences of participants. It is one of the first studies to give a voice to family-carers and women with LD who have declined to attend breast screening and has identified concerns about women with severe and profound LD attending screening. It also adds to the limited literature on the views of women with LD, paid-carers and allied-professionals. A key message these findings suggest is that breast screening should be viewed as a process and that the women, carers and allied-professionals have different influences at each stage of the breast screening process.

The main conclusion I drew from the findings was that the experience of breast screening for women with LD is negative, and little different from women in the general population. The exceptions to this were the women who had experienced breast cancer as they were more aware of the importance of attending for breast screening and were anxious to ensure that the cancer had not returned. They were able to differentiate the need to attend for mammography from the negative experience of the procedure. One woman had even developed a coping mechanism (naming the procedure as the 'orange squeezer') to distract her from the painful experience. What influenced the women to participate was inextricably linked to the woman's level of LD and the

preparation and support she received for breast screening. This was especially pertinent with regards women with severe and profound LD who invariably did not participate in breast screening due to being unable to understand or consent to the procedure. This provides new insight into factors that contributed to participation in breast screening for women with LD. The findings also revealed a need for innovative ways with which to enhance the experience of breast screening for these women, such as enabling their carers to be present during the procedure to support them or even standing alongside the women to assist the mammographers.

These findings demonstrated that there was evidence of equality of service provision but inequality of service delivery and up-take which has implications for breast screening units and for local policy development. It is hoped that these findings will sensitise mammographers to the experience of women with LD, making them more aware of the impact of their actions and how they are perceived. Consideration needs to be given to the breast screening system, as the current provision of six-minute appointments is too short to accommodate the needs of the women. More co-operation about data sharing was required to ensure breast screening units knew when women with LD had appointments. It was clear that more awareness training and support was needed to assist mammographers when working with women with LD. This could be achieved either through liaison nurses or specific training for mammographers in communicating and working with women with LD. Given that the main breast screening unit in my study had begun to make a DVD about breast screening, interest in this client group might facilitate development of a local policy in line with the needs of women with LD.

This study clearly demonstrated that the health experience of women with LD was very dependent upon which residential setting the women lived in, who supported them and with whom they came into contact. This has not been raised before and adds to the understanding of why some women are ill-prepared and simply do not attend breast screening. These differences suggest inequality within the service provision for these women.

The findings demonstrated that guardianship of the women's health was complicated, involving multiple layers of individuals who all aimed to support the woman but it remained unclear who had overall responsibility for the woman's health. This meant that these women were often unintentionally let down in terms of monitoring their health.

The findings also detected a tension between some allied-professionals and paid and family-carers, which suggested a lack of awareness about the role each played in the woman's care. A hierarchy was detected, with the health professional being considered the dominant authority on health matters. With cervical and breast screening, this relationship changed and the family-carers' views superseded those of both paid-carers and allied-professionals.

In general, paid-carers in this study wanted the best for the women but they, like the women, were let down by the lack of guidance offered within the service in which they worked. The paid-carers in this study also demonstrated knowledge and understanding of the need to monitor the women's breast health and were seen as integral to detecting changes in the woman's health status, a finding which challenged previous work within this area. What is urgently needed is a clear career structure to help retain care staff and a national policy that gives definitive guidance about supporting people with LD in health matters within the health and social care sectors.

Social inclusion strives to ensure that all women with LD should have access to services and this was generally found to be true of the women in this study. This may be because there has been a recent shift in government health policy towards determining why women with LD do not participate in breast screening. This may be indicative of increased government surveillance of women with LD in order to 'habituate them in to screening' and so be equal partners with woman in the general population. While the increase in attention towards the health of women with LD is welcomed, government health policy should also recognise the additional needs of these women to ensure that adequate provision is in place to allow needs to be met within current policy provision. At present there remains a tension between the health strategy of encouraging

attendance of women with LD at breast screening and a lack of resources to facilitate this. It is essential that these women's screening needs are met since the findings indicated that they have the same risk factors for breast cancer as women in the general population.

Having the same services as women in the general population and the need for additional support created a tension for women with LD in terms of social inclusion. Most women with LD in this study needed some support but, as the findings demonstrated, the quality and quantity of support depended upon the woman's level of LD and who was supporting her. In terms of breast screening, the findings indicated that the women were potentially being let down at all the different stages of the breast screening process, from the arrival of the invitation letter to the experience of having a mammogram. The reasons for this were associated with the environment in which the women lived within the social care sector. Professionals working with this client group were inexperienced, and a lack of understanding of the women's health needs prevented uptake of this service. Thus, although women with LD are included in breast screening programmes, they are not equal in terms of having their individual health needs addressed and the means to help them to maintain their health effectively are not being provided. To alleviate this more funding and training is required to support the women and a greater understanding about the roles that each of the allied-professionals, paid and family-carers play in supporting the women is needed. Only then will women with LD achieve social inclusion.

8.3.   Recommendations

The findings in this study have provided a clear picture of the experience of having a mammogram and the factors that influence participation in breast screening by women with LD. As a result, the findings of this study have implication for future practice, education and research.

8.3.1.   Recommendations for policy

- Clearer guidance is needed to establish the specific training requirements needed to ensure that people with LD are supported in all aspects of their daily lives, including health, in the social care sector. This may mean moving towards a professional basis with a clear career structure for paid-carers to help retain the workforce. This would need to be implemented at a national level in order to initiate such changes. The registration of support workers occurring at the end of 2011 in the UK is the first step towards professionalising the social care sector but there is a need to ensure the training requirements for those working with people with LD relates directly to the health needs of this client group.

- Effective collaboration between clinicians, patients and others has been called for by the Scottish Government's quality strategy (2010). It is essential for women with LD to be more involved in shaping the delivery of their health care. For those undertaking a professional training programme, a powerful resource to help understand the patient or client perspective would be an explanation of what is like to have a mammogram narrated by a woman with LD. This would be a useful resource for students in nursing, social work and radiography. The impact would be greater if it was delivered by women with LD than by a health professional or paid-carer.

- People with LD, especially women, are susceptible to obesity. To address such obesity and weight problems, leisure centres need to ensure the facilities they provide are accessible for the atypical population. This will need addressing if women with LD are to be supported to undertake exercise and engage in a more active lifestyle.

8.3.2.   Recommendations for practice

- A review and evaluation of the current educational resources available for women with LD about breast screening needs to be undertaken to ensure the quality of materials. On completion a central repository could

be developed such as an internet page in which materials could be placed for access by staff working in this area to preview before purchasing. There is also a need for more resources to be tailored to women with severe and profound LD and those who support these women.

- Review of the process entailed in attending for breast screening is needed for women with LD. There may be a need to extend the current provision of appointments beyond that of double appointments for these women. Consideration should be given to mammographers promoting more active involvement of paid-carers in the actual procedure, such as allowing them to stand alongside the woman whilst the procedure is undertaken.

- More inter-disciplinary working is needed to help understand the roles of those who work with people with LD and the services they provide. More interdisciplinary education and awareness for all health and social care professionals are essential if the health needs of people with LD are to be met. This would sit well within the current quality strategy (Scottish Government 2010).

- Alternatives to breast screening need to be provided for those women who are unable to attend mammography for reasons such as needing sedation or behavioural problems. Surveillance is one suggestion, as it could be undertaken during personal care. Alternatively, portable ultrasound equipment which can be used within the community could be considered. However, both surveillance and ultrasound have been found to be less accurate in detecting abnormalities.

8.3.3.   Recommendations for education

- There is a need to ensure practitioners who are not used to working with people with LD are supported. This would be a positive move forward in terms of patient-practitioner experience for both the client as well as the member of staff. One solution is the implementation of a liaison nurse

who supports practitioners who have less experience of working with people with LD.

- There is a need to ensure that GPs and key specialists receive regular training about the health needs of people with LD. It is imperative that a named specialist who develops an interest in LD within their specialism, for example, cardiology or colorectal surgery or even within a GP practice, is encouraged to meet the needs of these individuals. This would ensure there is continuity of care for presenting health needs.

8.4. Future research

A number of ideas for future work in this area were identified in the discussion but the main ones are as follows:

- Undertake a quality review of the current information and resources on breast awareness and breast screening aimed at women with LD. This could be undertaken by focus groups with women with LD, carers and health professionals. This could also aid the production of a range of breast awareness and breast screening materials tailored to a more diverse range of needs.

- A phenomenological study to investigate the entire patient journey from diagnosis of breast cancer through to its treatment in women with LD. This would help to understand the healthcare treatment that they receive and its impact on their quality of life. It would also give the women and those who support and treat the women the opportunity to comment systematically on the experience of this journey and to identify areas of poor practice.

- To undertake an epidemiological study investigating the incidence of breast cancer, especially familiar breast cancer, in women with LD. This would help to understand the incidence of cancer and improve knowledge about familiar breast cancer in this population.

- A cross-sectional designed study is required to investigate the views of family-carers, mammographers, GPs and other practitioners in supporting women with LD through breast screening.

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Appendix 1

Observation schedule:

Who was there – overview of the environment/background.

Prompts: What initiated the interaction?

What understanding did the woman have about the reason for appointment /talk

During the appointment/talk

What is said,

What is done

What is achieved

> **Prompts -**
>
> Who leads?
>
> Is person with LD involved?
>
> Information given – format
>
> Is there any checking out things with PLD by carer or medical personnel during the interaction?

After the interaction

What are people's perceptions of the appointment

Comments

Appendix 2

Ever been pregnant?

Appendix 2

Had your breasts checked by a doctor?

Appendix 3

Allied-professionals/paid-carers

Decision making about breast screening in women with learning disabilities

Identification number   age cohort

I am going to ask you some questions about keeping decision making and breast screening. Anything you tell me will be confidential, as only I will hear what you tell me. If there are any questions you do not want to answer just tell me and we can move on to the next one. If you do not understand a question just ask me to explain it to you. Remember you do not have to take part and can change your mind at anytime, including during the interview.

1. Personal experience

Can you tell me a something about your role?

Consider.....

      What is the title of your post? (if relevant)

      How long have you worked in your current post?

      How long have you been working with people with learning disabilities?

      Have you had any training for the work you do in your post in the last 12 months?

2. Breast awareness

How do the women keep themselves healthy?

Do the women/service users/residents here receive any education about breast screening/awareness ?

Prompts

Would you feel comfortable discussing issues such as breast screening/awareness?

Breast examinations, are they encourage? If yes are the examinations regular? Does your organisation have a code of practice for this?

Have you had any training on health issues in such as breast screening/examination?

Where do you think the women you care for get their knowledge about breast screening from?

3As we will be talking about breast screening could I ask what you understand about the procedure?

prompts: Have the women in your care ever been invited for breast screening?

Have any of the women in your care had breast cancer?

(If good rapport) Have you ever been for breast screening or had your breasts examined?

Have you accompanied or supported a woman in your care through breast screening?   Can you tell me about this?

Prompts: Who would be consulted about the breast screening invite?

Was any preliminary work done with the women?

What were the challenges for you?

. Information and training

Have you had any training on health issues in such as breast screening/examination?

.Decision making

Can you give me an example of how you have supported a resident/service user in making a breast screening /health care decision?

Prompts   Who is involved in this process?

How are general health care decisions made here?

What do you think are the major challenges on health care decision making in people with learning disabilities?

What do you think influences health care decision making in people with learning disabilities?

Anything else you want to add?

Interview: family-carers

Decision making about breast screening in women with learning disabilities

Identification number   age cohort

I am going to ask you some questions about keeping decision making and breast screening. Anything you tell me will be confidential, as only I will hear what you tell me. If there are any questions you do not want to answer just tell me and we can move on to the next one. If you do not understand a question just ask me to explain it to you. Remember you do not have to take part and can change your mind at anytime, including during the interview.

1. Personal experience

Can you tell me a little about yourself?

Consider.....

As well as caring for X do you also have a job?

What are your hobbies?

2. Breast awareness

How does X keep herself healthy?

Has anyone spoken to her about breast screening/awareness ?

Prompts

Would you feel comfortable discussing issues such as breast screening/awareness?

Does she undertake breast examinations

Have you had any training on health issues in such as breast screening/examination?

Where does she get her knowledge about breast screening from?

3As we will be talking about breast screening could I ask what you understand about the procedure?

prompts: Has X ever been invited for breast screening?/

Has X had breast problems?

(If good rapport) Have you ever been for breast screening or had your breasts examined?

If been for breast screening: If X has been to breast screening / if X was asked to go to breast screening.... Can you tell me about this/how you would approach it?

Can you tell me about this?

Prompts: Who would you consult about the breast screening invite?

Was any preliminary work done with her?

What were the challenges for you?

. Information and training

Have you had any training on health issues in such as breast screening/examination?

.Decision making

Can you give me an example of how you have/might support X in making a breast screening /health care decision?

Prompts   Who would you involved in this process?

How does X make general health care decisions?

What do you think are the major challenges on health care decision making in people with learning disabilities?

What do you think influences health care decision making in people with learning disabilities?

Anything else you want to add?

Interview for women with LD

Decision making about breast screening in women with learning disabilities

Identification number   DoB

I am going to ask you some questions about keeping your breasts healthy and how you make choices. If there are any questions you do not want to answer just tell me and we can move on to the next one. If you do not understand a question just ask me to explain it to you. Remember you do not have to take part and can change your mind at anytime, including during the interview.

1. **First of all I am going to ask you a few questions about yourself.**

Can you tell me something about yourself?

Prompts:

How long have you been living here/coming to …centre?

Have you ever been married? Partner? Boy-friend?

Do you have family of your own/ children?

2. **How do you keep yourself healthy?**

Prompts Have you ever smoked? ….. if so many

Do you drink alcohol?   … do you drink every day? How much do you drink? What do you drink?

Do you take any exercise…… if so what

3. **I am now going to ask you questions about keeping your breasts healthy**

Do you know how to keep your breasts healthy?

Prompts

Has anyone talked to you about keeping your breasts healthy?

Do you ever examine your breasts? Do you ever look at your breasts and feel them? ………..what do you look for?

4. I am now going to ask you about going for breast screening.

Have you heard of the term mammogram? Or breast screening? ....can you tell me more about this?

Prompts

Have you ever been asked to go to a special clinic to get your breasts examined– where a machine examines your breasts? If yes can you tell me about what it was like?

Do you know why women go for breast screening get their breast checked?

5. I am now going to ask you about how you make choices we also call this making decisions

How did you make up your mind to go/not go for breast screening?

Prompts:

Did anyone help you make this choice? Who

How do you make choices? Give an example....   Do you talk to anyone? Who do/would you talk to?

If you have a tricky problem how do you decide/choose what to do?

Is there anything you would like to ask me?

Appendix 4

Structure of field-notes

- Environment: what was the environment like, how did it feel

- People: interactions, behaviour, dress

- Key dialogues: during the visitor outwith the interview observation did the participant say anything worthy of noting

- Key points: relevant points about the participant, significant events, interests

- Reflections/perceptions: my thoughts, perceptions feelings, ideas, such as how things went, reflections on own life experiences that might influence the interaction and how I perceived it.

Appendix 5

Letter to carers

School of Nursing, Midwifery and Social Care
Napier University
74 Canaan Lane
Edinburgh
EH9 2TB
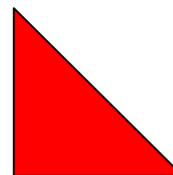
Email ▮▮▮▮▮▮▮▮▮▮▮

Telephone ▮▮▮▮▮▮▮▮▮▮▮▮

Date

An ethnographic study of decision making in relation to breast cancer screening for women with learning disabilities

Dear (name) member

I am inviting you to take part in a research study exploring how women with learning disabilities make decisions around breast screening.

Detailed information about the study is enclosed (see information sheet). The purpose of the study is to explore how women with learning disabilities make decisions around breast screening. Results from the study will be used to help improve the experience of breast screening for women with learning disabilities.

The study is run by myself, Diane Willis, and I am a nurse researcher currently working at Napier University in Edinburgh. I would like to speak to you to find out your views about breast screening and I may also ask if I could spend some time with you. The reason for spending time with you is that it gives more opportunity to find out about your experiences. Anyone wanting to take part in the study can just ask to take part in the discussion.

If you would like to take part in the study or wish further information, you should contact me, Diane Willis, on ▇▇▇▇▇▇▇▇▇or email me on

▇▇▇▇▇▇▇▇▇▇ Alternatively, you can complete the enclosed form, indicating whether you would like to take part in the study. This can be posted back to me in the stamped addressed envelope (if possible before 18th December 2007).

You are under no obligation to take part in this study and deciding not to take part will not influence your future treatment and care in any way.

Thank you for all your help

With kind regards

Diane Willis

Cancer Nursing Research Fellow

An ethnographic study of decision making in relation to breast cancer screening for women with learning disabilities

Name

…………………………………………………………………………….

Address

……………………………………………………………………………………

……………………………………………………………………………………

……………………………………………………………………………………

……………………………………………………………………………………

Telephone number …………………………………………………

Please tick the box of your preferred choice below:

I would like to take part in the interview only ☐

I would like to take part in both parts of the project ☐

I do not want to take part in the project. ☐

I would like to speak to Diane about the project ☐

Appendix 6

Consent and information sheets:
allied professionals

A research project to find out about decision making about breast screening in women with learning disabilities
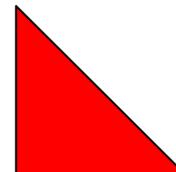
Some information for you to keep

What is in this leaflet?

You are being invited to take part in a research study. Before deciding to take part you need to know what the study is about and what it would involve

The research is to trying to find out how decisions are made about women with learning disabilities participating in the breast screening programme

I want to ask you what you think their needs are

Please take time to read this and talk to others about the study if you wish

Why have I been invited to take part?

You have been invited to take part because you have worked with a woman with a learning disability in a professional capacity

What will happen if you decide to take part?

If you decide to take part I will arrange a date to come and interview you. The interview will take between 30-45 minutes at a place of your choosing

You will be asked to sign a 'consent form' to confirm that you agree to take part and understand what the research study is about. I will also need confirmation that your line manager has given you permission to take part in this study

Anything you say will remain confidential and your line manager will not be informed about what we discuss

During the interview I shall ask you some questions for example about how you and the woman/women you work/have worked with make decisions, issues

about breast screening and what you think can be done to help them. I shall also ask you about some personal information, for example your age, whether you have attended breast screening, how long you have been in your chosen profession.

If you do not want to answer a question please tell me and we can move on to the next question

I will want to tape the interview because I will not be able to write down everything you say. If you don't want me to tape the interview, I will just take notes

After the interview I may ask if I can spend some time with to observing what you do in your practice. This will help me understand what you do and how you make decisions

If you agree I shall come to your work place for a few hours over three days to see what you do

If you do not want to take part in this part of the research please tell me

You can change your mind about whether you want to take part at any time, including during the interview or observation

What are the possible benefits of taking part?

We hope that by exploring the issue of breast screening the experiences of women with learning disabilities attending for breast screening will improve

What are the possible disadvantages of taking part?

Some people find it upsetting talking about breast screening, especially if you or a relative have had breast cancer. If this happens then with your permission I can put you in touch with someone who can help you

If you do not want to take part

Participation is entirely voluntary. If you choose not to no one will know your decision

What about the tapes and what we say

The tapes and everything we say will remain confidential. No one other than my research supervisors and myself will know what we have discussed

The tapes have to be kept for 5 years after the research ends unless you ask for them to be destroyed sooner. The tapes will be kept in a locked office, in a locked cabinet at the University

Anything you tell me may be used in the research but no records will have your name on it and your confidentiality will be kept throughout

I may publish the findings in a journal but your anonymity will be protected

What do you need to do

You need to decide whether you want to take part

Feel free to talk to friends and colleagues about this project
You may also want to talk to someone else, you can talk Dr Maureen Macmillan. Her address and telephone number are on this leaflet (see below)

If you want to know more about the project contact:

Diane Willis, Research Fellow School of Nursing, Midwifery and Social Care, Napier University, 74 Canaan Lane Site, Edinburgh EH9 2TB. Tel: ███████
███ Email ██████████████

Dr Maureen Macmillan, Senior Lecturer, School of Nursing, Midwifery and Social Care, Napier University, 74 Canaan Lane Site, Edinburgh EH9 2TB. Tel: █████████████Email ██████████████████

Thank you for reading this!

Diane Willis

Carers information sheet
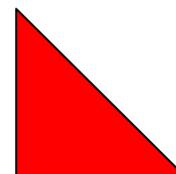
What is in this leaflet?

You are being invited to take part in some study

This leaflet tell you what it is about

The research is to trying to find out how decisions are made about women with learning disabilities participating in the breast screening programme

I want to ask you what you think their needs are

Please take time to read this and talk to others about the study if you wish

Why have I been invited to take part?

You have been invited to take part because you care for a woman with a learning disability.

What will happen if you decide to take part?

If you decide to take part I will arrange a date to come and interview you. This will take between 30-45 minutes at a place of your choosing

I will be asked to sign a 'consent form' to confirm that you agree to take part and understand what the research study is about. If you are a paid carer I will also need to know that your line manager has given you permission to take part in this study

Anything you say will remain confidential, and that your line manager will not be informed about what we discuss

During the interview I shall ask you some questions for example about how you and the woman/women you care for make decisions, issues about breast screening and what you think can be done to help them. I shall also ask you about some personal information, for example your age, whether you have attended breast screening and how long you have been a carer

If you do not want to answer a question you only have to say so

I will want to tape the interview because I will not be able to write down everything you say. If you don't want me to tape the interview, I will just take notes

After the interview I may ask if I can spend some time with to see what you do during the day. This will help me understand what you do and how you make decisions

If you agree I shall come to your work place/home for a few hours over three days to see what you do

If you do not want to take part in this part of the research you only have to say so

You can change your mind about whether you want to take part at any time, including during the interview or observation

What are the possible benefits of taking part?

I hope that by exploring the issue of breast screening the experiences of women with learning disabilities attending breast screening will be improved

What are the possible disadvantages of taking part?

Some people find it upsetting talking about breast screening, especially if you or a relative have had breast cancer. If this happens then with your permission I can put you in touch with someone who you can talk to and who can help you

If you do not want to take part
Participation is entirely voluntary. If you choose not to take part no one will know except you and me

What about the tapes and what we say

The tapes and everything we say will remain confidential. No one other than my research supervisors and myself will know what we have discussed

The tapes have to be kept for 5 years after the research ends unless you ask for them to be destroyed sooner. The tapes will be kept in a locked office, in a locked cabinet at the University

Anything you tell me may be used in the research but no records will have your name on it

I may publish the findings in a journal but your name will not appear on anything

What do you need to do

You need to decide whether you want to take part

Feel free to talk to friends, family and colleagues about this project

You may also want to talk to someone else, you can talk Dr Maureen Macmillan. She is an independent adviser and is not involved with the research but may be able to give advice. Her address and telephone number are on this leaflet below

If you want to know more about the project contact:

Diane Willis, Research Fellow School of Nursing, Midwifery and Social Care, Napier University, Canaan Lane Site, Edinburgh EH9 2TB. Tel: ▮▮▮▮▮▮ Email ▮▮▮▮▮▮▮▮▮▮▮▮

Dr Maureen Macmillan, Senior Lecturer, School of Nursing, Midwifery and Social Care, Napier University, Canaan Lane Site, Edinburgh EH9 2TB. Tel: ▮▮▮▮▮▮ Email ▮▮▮▮▮▮▮▮▮▮

Thank you for reading this!

Diane Willis

Information sheet for women with LD

A research project to find out about decision making about
 breast screening in women with learning disabilities
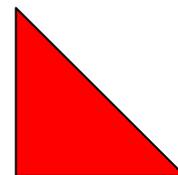
Some information for you to keep

What is in this leaflet?

You are being invited to take part in a research project

This leaflet tells you about the project

What is the project about?

I want to find out how women keep their breasts healthy

The project is looking at breast screening. Breast screening is where women have their breasts examined by a machine. The machine takes a picture of their breasts. This is what we call having a mammogram

What will happen if you decide to take part?

I will make a date to come and talk to you about the project

I will phone you a week later to see that you still want to take part

I will make a date to meet you at your house or somewhere else if you prefer where we can talk

You will need to sign a special piece of paper called a 'consent form'. This 'consent form' means that you want to take part in my project

I will ask you some questions. I will ask about how you keep your breasts healthy

If you don't want to answer the questions that's ok

I will tape-record what we talk about. This is because I will not be able to write down everything we say

If you don't want me to tape-record our talk that is ok

Sometimes you might not understand the questions but I can help you. There are no right or wrong answers. It is not a test

I may also ask if I can come and spend time with you. I will be watching what you do. This is called being observed

If you do not want me to watch you that's OK

You can change your mind about taking part at any time – even during the interview

What about the tapes and what we say?

The tapes and what we say will be private. Only I will know what you said

If you tell me something bad has happened to you I will need to tell someone about this. They will then be able to help you

No one will know I spoke to you or who you are – we call this being anonymous

I may publish what I find out in a special magazine. We call this special magazine a journal

We have to keep the tapes for 5 years. You can ask me to destroy them sooner. The tapes will be kept in a locked cabinet at my work

What do you need to do?

Think about whether you want to take part

Show friends this leaflet and talk to them about the project
You may want to talk to someone else; you can talk to Maureen Macmillan. Her address and telephone number is on this leaflet

What if you do not want to take part?
It's OK

Only you and I will know that you did not want to take part

If you want to know more about the project contact:

Diane Willis, Research Fellow School of Nursing, Midwifery and Social Care, Napier University, Canaan Lane Campus, Edinburgh EH9 2TB. Tel: ███████
███Email ███████████████

Maureen Macmillan, Reader, School of Nursing, Midwifery and Social Care, Napier University, Canaan Lane Campus, Edinburgh EH9 2TB. Tel: ███████ ████ Email ████████████████████

Thank you for reading this!

Diane Willis

Easy read flyer

My name is Diane Willis and I work on the project.

I want to: speak to and listen to the thoughts of your carers and others who help you about going for breast screening.

I want to listen to what women with learning disabilities know and feel about going for breast screening (where you go to a special clinic to have a picture (X-ray) taken of your breasts).

I want to: speak to and listen to the thoughts of your carers and others who help you about going for breast screening.

I want to find out how nurses, doctors and others who care for you can give you the help and support you need when you go for breast screening.

If you would like more information about the project or would like to take part in the project please telephone me on:

If I'm not in the office, please leave your telephone number and name and I will call you back as soon as I can.

Diane Willis
Napier university
74 Canaan Lane
Edinburgh

Napier University
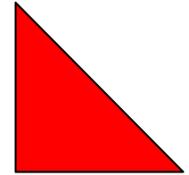
A project bout making choice about keeping your breasts healthy

Consent form allied-professionals, paid and family-carers
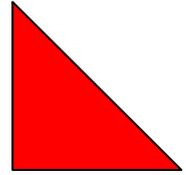
Decision making about breast screening in women with learning disabilities

Identification number:

1. I confirm that I have read the information sheet for the above study. I understand what the study is about and I have had the opportunity to ask questions about it.

2. I have not been made to take part and I know that I can say no at any time without giving any reason, without anyone else knowing.

3. I have said yes and want to take part in the above study.

4. My line manager has given me permission to take part in the research study (allied-professionals and paid-carers)

Name of participant   …………………………………………..

Date ………………………. Signature ………………………….

Name of researcher taking the consent …………………………………

Date ……………..   Signature of researcher……………………

Consent form (women)
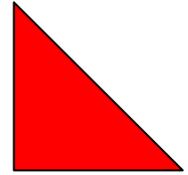
Decision making about breast screening in women with learning disabilities

Identification number:

1. I confirm that I have read/have had read to me the information sheet for the above study. I understand what the study is about and I have had the opportunity to ask questions about it.

2. I have not been made to take part and I know that I can say no at any time without giving any reason, without anyone else knowing.

3. I have said yes and want to take part in the above study.

Name of participant   …………………………………………..

Date ……………………. Signature ………………………….

Name of researcher taking the consent ……………….................

Date ………………..

 Signature of researcher…………………………………

Pictorial consent:

My name is Diane

May I ask you some questions?

√   X
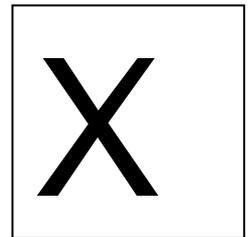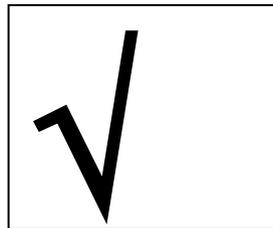
May I tape what we say?
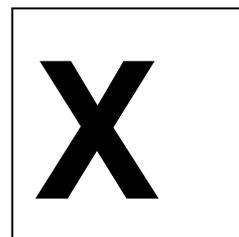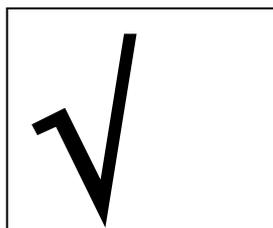
√   X

Name of participant   …………………………………………..

Date ……………………. Signature ………………………….

Name of researcher taking the consent ………………………………

Date ……………….   Signature of researcher…………………

Appendix 7

Ethics permission

Scotland A Research Ethics Committee

Secretariat
Deaconess House
148 Pleasance
Edinburgh
EH8 9RS
Telephone 0131 536 9026
Fax 0131 536 9346
www.corec.org.uk

NHS SCOTLAND

Ms Diane S Willis
Cancer Nursing Research Fellow
Napier University
School of Nursing, Midwifery and Social Care
74 Canaan Lane
Edinburgh
EH9 2TB

Date: 20 May 2009
Your Ref.:
Our Ref.: 07/MRE00/23

Enquiries to: Walter Hunter
Extension: 89026
Direct Line: 0131 536 9026
Email: walter.hunter@lhb.scot.nhs.uk

Dear Ms Willis

Study title: **An ethnographic study of decision making in relation to breast cancer screening for women with learning disabilities**

REC reference: **07/MRE00/23**

This study was given a favourable ethical opinion by the Committee on 26 April 2007.

It is a condition of approval by the Research Ethics Committee that the Chief Investigator should submit a progress report for the study 12 months after the date on which the favourable opinion was given, and then annually thereafter. To date, the Committee has not yet received the annual progress report for the study, the first of which was due on 26 May 2008. It would be appreciated if you could complete and submit the report by no later than 30 June 2009.

Guidance on progress reports and a copy of the standard NRES progress report form is available from the National Research Ethics Service website.

The NRES website also provides guidance on declaring the end of the study.

Failure to submit progress reports may lead to a suspension of the favourable ethical opinion for the study.

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees (July 2001) and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

Chairman Professor Kennedy Lees
Vice-Chairman Dr Malcolm Booth

NHS
SCOTLAND

Yours sincerely

Walter Hunter
Committee Co-ordinator

NHS SCOTLAND

09 June 2008

Ms Diane S Willis
Cancer Nursing Research Fellow
School of Nursing, Midwifery and Social Care
74 Canaan Lane
Edinburgh
EH9 2TB

Dear Ms Willis

Study title: **An ethnographic study of decision making in relation to breast cancer screening for women with learning disabilities**
REC reference: 07/MRE00/23
Amendment number: **No 1**
Amendment date: **28th April 2008**

The above amendment was reviewed at the meeting of Scotland A Research Ethics Sub-Committee held on 2nd June 2008.

Ethical opinion

The members of the Committee present gave a favourable ethical opinion of the amendment on the basis described in the notice of amendment form and supporting documentation.

The documents reviewed and approved at the meeting were:

Document	Version	Date
Notice of Substantial Amendment (non-CTIMPs)		15 May 2008
Covering Letter		15 May 2008

Membership of the Committee

The members of the Committee who were present at the meeting are listed on the attached sheet.

Chairman: Professor Kennedy Lees
Vice Chairman: Dr Malcolm Booth

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Scotland A Research Ethics Committee

R&D approval

All investigators and research collaborators in the NHS should notify the R&D office for the relevant NHS care organisation of this amendment and check whether it affects R&D approval of the research.

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees (July 2001) and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

07/MRE00/23:	Please quote this number on all correspondence

Yours sincerely

Mrs Dorothy Garrow
Committee Co-ordinator